Real Choice Systems Change Grant Program

Second Year Report

(October 1, 2002 – September 30, 2003)

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(October 1, 2002–September 30, 2003)

Final Report

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Overview

As part of President George W. Bush's New Freedom Initiative, Congress provided funds for the Real Choice Systems Change Grants for Community Living Grants program in fiscal years 2001 through 2003. The funds support the creation of long term care (LTC) systems that enable people with disabilities or long-term illnesses to live in their own homes or in other residential settings, and to have more control over the services they receive. The purpose of the grants is to encourage states to make enduring changes in their LTC systems that will enable people of all ages with a disability or long-term illness (1) to live in the most integrated community setting suited to their needs, (2) to have meaningful choices about their living arrangements, and (3) to exercise more control over the services they receive.

Bringing about change in any state's system is a complex, long-term endeavor requiring the involvement of many public and private entities at multiple levels. Recognizing this, the grants are intended to be catalysts for incremental systems change—to support new or expand existing systems change initiatives—with the goal of enabling enduring changes in key system areas. CMS has awarded approximately $158 million in Systems Change grants to 49 states, Guam, the Northern Mariana Islands, and the District of Columbia. In all, 174 grants have been awarded across three fiscal years—2001 through 2003—not including technical assistance grants. The implementation period for each grant is 3 years.

The purpose of this report is to describe the FY 2001 and FY 2002 Grantees' accomplishments and progress, using information provided by the Grantees during the reporting period October 1,

2002 to September 30, 2003 (Year Two of grant period for FY 2001 Grantees and Year One of grant period for FY 2002 Grantees). The report describes grant activities in six major LTC systems areas:

- Consumer Direction and Control—efforts to give consumers more control over the home and community LTC services and supports they receive.
- Access to Long Term Care Services and Supports—efforts to ensure that consumers have access to the full range of home and community LTC services and supports.
- State Budgeting and Reimbursement Rates and Methodologies—efforts to develop budgeting or reimbursement initiatives to make long term care systems more consumer oriented, accessible, efficient, and cost effective.
- Service Creation/Modification—efforts to create or modify LTC services and supports to better support consumers' ability to live in the community.
- Long Term Care Service and Support Workforce—efforts to improve the recruitment and retention of direct service workers, to address problems associated with the shortage of these workers and their impact on personal assistant services.
- Quality Management Mechanism—efforts to design, implement, and maintain quality assurance and improvement systems suited to community living.

In each of these six areas, the report describes Grantees' accomplishments, outcomes realized, work products, evaluation plans and activities, problems/issues with particular activities, and enduring changes made, including the enactment of new legislation and policies. We also describe challenges they faced implementing grant activities and the role of consumers and consumer partners in the oversight and implementation of grant activities.

The principal source of data for this report is the Year Two annual reports of the 52 FY 2001 Grantees and the Year One annual reports of the 49 FY 2002 Grantees, which were submitted electronically using a web-based reporting system.

The information contained in this report is subject to the limitations of the data and the technical approach used. Specifically, the content of this report depends on both the quality and thoroughness of each Grantee's responses in their annual report and their responses to follow-up inquiries. Some activities overlap focus areas, and RTI exercised judgment in assigning activities to a

particular area and categories within these areas. At each step of the analysis, RTI exercised judgment to determine the key activities and issues to highlight in this report. Staff eliminated duplicative information and prepared concise summaries. Consequently, descriptions of activities may not contain some information that individual Grantees consider important.

FINDINGS

Consumer Direction

Grantees in 41 states reported activities to incorporate the principles of consumer direction in service delivery and to increase consumer direction and control by developing and implementing (1) administrative rules and regulations; (2) legislation and executive orders; (3) pilot projects or model programs; and (4) training and education for consumers, families, and providers.

Many states' activities focused primarily on bringing about changes in administrative rules and regulations and providing education and outreach to consumers. For example, **Nebraska (RC)** reviewed regulations across the health and human services system and worked to revise the personal assistance service regulations to incorporate principles of consumer direction. As a result, the State developed a statute allowing consumers the right to choose among the array of available services. **Indiana (RC, CPASS)** incorporated consumer-directed care into draft policy for the Indiana Bureau of Aging and In-Home Services, and has also incorporated the principle of consumer direction into a new draft state rule on services for the aged and disabled.

A few states are conducting pilot projects or pursuing changes in legislation or executive orders. **South Carolina (RC)** developed and implemented the first of two pilot projects under *SC Choice*. The pilot was implemented in September 2003 and is serving a small number of consumers. Policies and procedures relating to consumer direction in *SC Choice* were also developed and integrated into the Community Long Term Care Program.

Access

Grantees in all states except New Mexico reported undertaking activities to provide or increase access to new or existing services and supports. The initiatives described by Grantees include efforts

to improve access by (1) integrating information sources for multiple long term care services and supports; (2) streamlining financial and functional eligibility determinations; (3) expanding eligibility; (4) creating transition processes and transitioning and diverting individuals to community settings; (5) increasing informed consumer choice; and (6) increasing the availability of housing, transportation, and other community supports.

The majority of states have been working to improve access by integrating information sources, transitioning individuals, ensuring consumer choice, and addressing the availability of other community supports including housing. **Arkansas (RC, CPASS, NFT)** Grantees worked together to develop a statewide website (http://www.argetcare.org/) to serve as a single point of entry for the Divisions of Developmental Disabilities and Aging and Adult Services. The website includes service definitions, a self-assessment tool, a provider directory by geographic area, and links to provider websites.

During this reporting period, in 22 states, 24 Grantees reported successfully transitioning a combined total of 1,214 consumers to community settings and diverting 41 consumers from entering nursing facilities or other institutions. **Connecticut (NFT)** transitioned 31 individuals in Year Two of its grant and published a transition self-assessment tool and a step-by-step transition guide. The Grantee also worked with the State's Medicaid Infrastructure Grant (MIG) to help transitioned individuals find work.

Missouri (RC) developed a training curriculum, *Informed Choice*, to increase awareness among guardians and those who work with them about consumer choice. Using a train-the-trainer approach, the Grantee completed a pilot program using the curriculum and has begun phase-in of statewide *Informed Choice* training for judges, public administrators, attorneys, and others involved with guardianship activities.

Many Grantees are involved in a range of activities to increase access to community supports including housing, transportation, and assistive technology. **Tennessee (RC)** has hired local consumer housing specialists to help complete the "Housing Within Reach" website (http://www.housingwithinreach.org/). This website provides information about housing options and other housing-related issues. The consumer housing specialists are also disseminating information regarding housing options at drop-in

centers, community meetings, and housing-related State meetings.

A few Grantees are engaged in efforts to streamline or expand eligibility to Medicaid state plan or home and community-based services (HCBS) waiver programs. **Washington (NFT, RC)** developed a comprehensive assessment tool and a cross-systems case management model for determining eligibility and assessing services needs across all disability populations. **Massachusetts (RC)** is testing a pilot program to provide services for individuals currently not eligible for the Medicaid Personal Care Attendant Program.

State Budgeting and Reimbursement

Grantees in 38 states are exploring, developing, and implementing budget or reimbursement initiatives to make their long-term care systems more consumer-oriented, accessible, efficient, and cost effective. Their initiatives fall into four categories: (1) individualized budgeting, (2) payment rates and methodologies, (3) Money Follows the Person, and (4) consolidated budgets.

The majority of these states have initiatives to provide individualized budgeting options and initiatives to reform payment rates and related methodologies. **Oregon (RC)** is operating a mental health brokerage demonstration project for up to 25 mental health service participants, which gives them control over a $3,000 budget for up to 18 months. The funds can be used to purchase products and services to aid in their recovery. **West Virginia (CPASS)** staff is working with the Bureau for Medical Services to establish an equitable payment methodology for consumers who choose consumer direction to "cash out" funds that have been authorized for services within the Aged and Disabled Waiver. The methodology will likely be based on the monetary amounts associated with a participant's level of care as determined by eligibility assessments and re-assessments.

Over a third of the 38 states are working on Money Follows the Person initiatives. **Wisconsin (NFT, NFT-ILP)** helped develop statutory and other provisions establishing a mechanism for money to follow the person from intermediate care facilities for people with mental retardation (ICFs/MR) to the community. Using these provisions, **Wisconsin (RC)** is exploring options for ICF/MR funds

to follow residents who transition to home and community services.

A few states have initiatives focusing on consolidated budgets. For example, **Oklahoma (RC)** is developing a model managed care service delivery system that combines delivery and reimbursement of acute and LTC services for persons in a single program.

Service Creation/Modification

Grantees in 41 states have a wide range of initiatives to create new or modify existing home and community services. These initiatives are grouped into three categories: (1) transition services, (2) personal assistance services, and (3) consumer-directed services. In over half of the states, Grantees are working on initiatives to create services or modify personal assistance services to make them more consumer-responsive. For example, **Massachusetts (RC)** implemented a pilot program that allows consumers to hire independent workers, including friends and relatives. As part of this pilot, consumers have individualized budgets, and they design their spending plan with support from a community liaison.

Grantees in a number of states are supporting the transition of persons with disabilities into the community by providing transition services not funded by other sources. For example, **South Carolina (NFT)** provided clients that have immediate transition needs with special service packages and other items, including groceries, bathroom safety aids, a limited amount of furniture, nutritional supplements, and home modifications.

Several Grantees are working to create consumer-directed options in existing programs. **Maine (RC)** is working to amend existing HCBS waiver programs to incorporate a consumer-directed option, and **New Hampshire (CPASS)** successfully implemented a new consumer-directed personal care option in its HCBS waiver program for elderly and chronically ill persons. **Nebraska (RC)** worked to revise regulations for the State's Personal Assistance Services program, to give consumers the option to hire, train, and direct workers to perform health maintenance tasks that previously had been covered by the State's Nurse Practice Act.

Workforce

Grantees in 39 states have workforce initiatives to improve the recruitment and retention of workers and the quality of direct care services. These initiatives fall into five categories: (1) recruitment

efforts, (2) wage and benefit improvements, (3) training and career ladders, (4) changes in the work culture, and (5) systems administration and planning.

Grantees in approximately half of the 39 states have initiatives focusing on recruitment and/or training and career ladder development. **Maryland (RC)** job fairs were successful in recruiting new providers for their HCBS waiver programs, enrolling 100 persons at the first fair. These regional job fairs targeted self-employed direct service workers who had expressed an interest in providing personal assistance services through the waiver program. The fairs provided needed training, certification, and background checks in a single venue. Of those job fair participants who were tracked, approximately 51 percent went on to become providers. **North Carolina (RC)** is planning its first Direct Care Worker Institute sponsored by the State's new direct service worker association to provide educational training. The target audience includes direct care workers, providers, consumers, family members, and other interested individuals. The Grantee has also arranged for staff from the Paraprofessional Healthcare Institute to provide train-the-trainer sessions on coaching and supervision skills for 44 workers.

In 18 states, Grantees have wage and benefit initiatives. For example, the **District of Columbia (RC, CPASS)** worked to increase the reimbursement rate for workers by $2.00 per hour, and is reviewing wages in contiguous states to develop a competitive wage scale that will attract individuals to the direct service workforce.

In a few states, Grantees are pursuing initiatives aimed at promoting work culture change and improving systems administration and planning. **Maine (RC)** has developed the Personal Assistance Workers' Association to represent the interests of direct service workers. **Michigan (CPASS)** petitioned the Governor to authorize the development of a public authority model for employing direct care workers after conducting a needs assessment on the State's workforce issues. The Grantee developed a plan for a public authority model that will provide training that can lead to the development of career ladders and help workers obtain benefits such as a low-income health care plan, subsidized housing, and tax credits. The public authority's registry will help workers find additional consumers in need of backup assistance when they want to increase their hours worked.

Quality Assurance

Grantees in 25 states have implemented initiatives to improve the quality of services. The quality initiatives fall into three broad categories: (1) adding a consumer focus to the quality monitoring system, (2) developing data systems for quality monitoring, and (3) developing and implementing specific components of quality management systems, including consumer-focused quality assurance tools, processes, or consumer satisfaction surveys.

Grantees primarily reported adding a consumer focus to quality management systems and developing and implementing consumer-focused components of quality management systems. For example, **Maine (RC)** has developed a consumer-driven approach to quality management that enables those receiving home and community services to define quality. To ensure that the quality indicators were consumer-focused, the Grantee involved consumers as well as experts and policymakers in their development. The State has created a web-based database of quality measures for home and community services organized according to the HCBS Quality Framework (http://qualitychoices.muskie.usm.maine.edu/qualityindicators/index.htm). **Virginia (RC)** is addressing gaps in quality assurance and lack of satisfaction with HCBS waiver programs through the development of performance, outcome, and satisfaction measures. The State has also been pilot testing a quality assurance program for its Elderly and Disabled waiver program, which includes a client satisfaction survey.

A few Grantees are developing data systems for quality monitoring. For example, **Oklahoma (RC)** has developed a new contracting infrastructure that requires all Medicaid Personal Assistance Services and 1915(c) ADvantage waiver provider agencies to have an approved continuous quality improvement plan. The State is also developing a Quality Waiver Evaluation System Tracking (QWEST) software system, which will include a statewide consumer complaint/concern discovery and remediation system for ADvantage waiver participants. **Washington (RC)** has developed a new quality assurance system that will allow the State to retrieve data on deficiencies, and a monitoring system for incident and mortality reports, to identify trends and patterns. The information will be used to improve policy, staff training, and consumer services.

Challenges

While Grantees have made significant progress initiating and implementing grant activities, many Grantees described challenges related to their LTC systems change activities as well as administrative challenges. Generally, the challenges are unique to their individual efforts to improve the LTC systems in their respective states. The primary administrative challenges Grantees described were finding staff for grant activities, state budget deficits, and delays in subcontracting.

Consumer Involvement

In keeping with congressional intent, Grantees are involving consumers in grant planning and implementation in a variety of ways. Consumers serve as members of consumer task forces and advisory committees and, in this capacity, provide oversight for all grant activities. Consumers are also assisting in grant implementation, by providing input on specific grant activities in focus groups, meetings, and other venues. Finally, Grantees are soliciting the consumers' input to assess the grant's impact through consumer satisfaction surveys and focus groups.

LOOKING FORWARD

The Systems Change grants are providing seed money for a multi-year effort to build the state infrastructure needed to provide consumer-responsive LTC systems. CMS allowed Grantees exceptional flexibility in selecting the initiatives they believe will yield the most significant improvement in their state's home and community service system.

As the findings illustrate, at the end of Year Two of the grant program, states are engaged in a wide range of LTC Systems Change activities, and are involving consumers and other stakeholders in their efforts. In many states, Grantees are combining resources across multiple Systems Change grants—as well as Medicaid Infrastructure grants and other sources of funding—to leverage resources and coordinate systems change efforts.

Though the FY 2001 Grantees are at the end of the 3-year grant period—September 2004—virtually all have received no-cost extensions to continue grant activities for a fourth year. Most will be completing activities that had a late start, evaluating their grant

activities, and working to ensure that Systems Change initiatives are sustained after the grant ends.

The FY 2002 Grantees will continue to focus on grant implementation and evaluation in their third year. Due to delays in grant initiation, we expect that a large number of these Grantees will also apply for no-cost extensions to enable the completion of grant activities.

The Third Annual Report will contain information on the Year Two activities of the FY 2002 Grantees and the Year One activities of the FY 2003 Grantees.

RTI will produce a final report for each FY Grantee group, based on information they provide in their final reports and evaluations. RTI's final reports will present information about each state's accomplishments across all of the grants awarded in the same fiscal year.

1 Introduction

1.1 BACKGROUND

Historically, the majority of public funding for long term care (LTC) has paid for the provision of services in institutional settings. Over the past 20 years, many states have led the way in creating LTC systems that enable people with disabilities or long-term illnesses to live in their own homes or in other residential settings and to have more control over the services they receive. The 1999 Supreme Court decision in Olmstead v. L.C. gives legal weight to this policy direction. However, despite the movement to rebalance LTC systems in virtually all states, the majority of funding for LTC services continues to be spent on institutional care—71 percent in 2001 and 67 percent in 2003.[1,2]

In fiscal years 2001 through 2003, Congress provided funds for a grant program to help states and others identify and implement methods to increase access to, and the availability, quality, and value of, home and community-integrated services. Beginning in May 2001, the Centers for Medicare & Medicaid Services (CMS), as part of the President's New Freedom Initiative, has invited applications from states and other entities to apply for Real Choice Systems Change Grants for Community Living (*hereafter,* the Systems Change grants). The purpose of the Systems Change grants is to encourage states to make enduring changes in their LTC systems that will enable people of all ages with a disability or long-term illness to (1) live in the most integrated community setting suited to their needs, (2) have meaningful choices about their living arrangements, and (3) exercise more control over their services.

Bringing about change in any state's system is a complex long-term endeavor requiring the involvement of many public and private entities at multiple levels. Recognizing this, the Systems Change grants are intended to be catalysts for incremental systems change—to support or expand existing systems change initiatives—and to enable states to make enduring changes in key system areas.

CMS has awarded approximately $158 million in Systems Change grants to 49 states, Guam, the Northern Mariana Islands, and the District of Columbia. In all, 174 grants have been awarded across three fiscal years (FY), 2001–2003, not including technical assistance grants. Exhibit 1 summarizes the types of grants awarded in FY 2001 and FY 2002. Appendix A lists the types of grants awarded in FY 2001 and FY 2002 and the total amount awarded to each state. Appendix B identifies the lead agency receiving grants in each state in FY 2001 and FY 2002. For information on the FY 2003 Grantees, see Appendix C.

Exhibit 1. Number of Systems Change Grants Awarded, by Grant Type

Grant Type	FY 2001 & FY 2002
Real Choice (RC)	50
Community-Integrated Personal Assistance Services (CPASS)	18
Nursing Facility Transition (NFT)*	33
Total	**101**

*NFT Grants are of two types—State Program (SP) Grants supporting state initiatives, and Independent Living Partnership (ILP) Grants made to Centers for Independent Living (CILs) to promote partnerships between CILs and states to support transitions to the community. In this report, NFT refers to state program grants, whereas NFT-ILP refers to the latter type.

1.2 PURPOSE AND ORGANIZATION OF REPORT

The purpose of this report is to describe the FY 2001 and FY 2002 Grantees' accomplishments and progress during the reporting period October 1, 2002, to September 30, 2003, as reported by the Grantees. For the FY 2001 Grantees, this report covers Year Two of a 3-year grant period, and for the FY 2002 Grantees, it covers Year One of a 3-year grant period.

The report has four sections and several appendices. Section 2 describes the data sources used to prepare this report and the technical approach for summarizing and reporting the data.

Section 3 describes grant activities in six major areas of systems change:

- *Consumer Direction and Control*—efforts to give consumers more control over the home and community LTC services and supports they receive.
- *Access to Long Term Care Services and Supports*—efforts to ensure that consumers have access to the full range of home and community LTC services and supports.
- *State Budgeting and Reimbursement Rates and Methodologies*—efforts to develop budgeting or reimbursement initiatives to make LTC systems more consumer oriented, accessible, efficient, and cost effective.
- *Service Creation/Modification*—efforts to create or modify LTC services and supports to better support consumers' ability to live in the community.
- *Long Term Care Service and Support Workforce*—efforts to improve the recruitment and retention of direct service workers and to address consumer problems associated with the shortage of these workers.
- *Quality Management Mechanism*—efforts to design, implement, and maintain quality assurance and improvement systems suited to community living.

In each of these six areas, the report describes Grantees' accomplishments, outcomes realized, work products, evaluation plans and activities, problems/issues with particular activities, and enduring changes made, including the enactment of new legislation and policies. We also describe challenges they faced initiating and implementing grant activities and the role of consumers and consumer partners in the oversight and implementation of grant activities.

The final section provides information about future reports on the grant activities of the FY 2001 and FY 2002 Grantees.

2 Methods

2.1 DATA SOURCES

Our principal source of data is the Year Two annual reports of the 52 FY 2001 Grantees and the Year One annual reports of the 49 FY 2002 Grantees. Additional information was obtained through e-mail communication and telephone calls with many Grantees.

2.2 TECHNICAL APPROACH

RTI, with the support of its subcontractor, The MEDSTAT Group, created an Access database comprising Grantees' annual report responses and generated a series of analytic reports to examine data by response category and state across Grantees. After reviewing the data, RTI staff contacted Grantees to obtain additional information and to clarify responses. Based on an analysis of the responses, we identified categories within six major focus areas, which we used to classify Grantee initiatives in each state (including the District of Columbia, Guam and the Northern Mariana Islands). Finally, we selected examples of Grantee activities in these categories to illustrate the type and range of activities during the reporting period.

2.3 LIMITATIONS OF THE APPROACH

This report describes the progress Grantees have made on their scheduled activities in the reporting period. The description is subject to the limitations of the data and the technical approach used. Specifically,

- The data used in the analysis were reported by Grantees. The content of this report depends on both the quality and

thoroughness of each Grantee's responses in their annual report and their responses to follow-up inquiries.

- In some cases, activities overlap focus areas. For example, nursing facility transition activities could be assigned to both the Access focus area as well as the Service Creation focus area. Consequently, RTI exercised judgment in assigning activities to a particular focus area and categories within these areas. However, in most instances we assigned activities to those focus areas that Grantees identified. In some instances, different facets of the same initiative are described in more than one focus area.
- At each step of the analysis, RTI exercised judgment to determine the key activities and issues to highlight in this report. Staff eliminated duplicative information and prepared concise summaries. Consequently, descriptions of activities may not contain some information that individual Grantees consider important.
- When responses indicated that Grantees misinterpreted a question, or responses did not include sufficient detail, they were not included in our analysis.
- This report covers only one year of Grant activities. Therefore, Grantees may not have reported some activities that have been completed or have not yet been initiated.

3 Findings

As discussed in Section 1.2, Grantees' activities for the reporting period are categorized into six systems change focus areas. Many states have more than one Systems Change grant, enabling them to develop and implement initiatives in multiple areas. As Exhibit 2 shows, most states are involved in activities spanning several focus areas. Almost all are focusing on increasing access to and improving the quality of LTC supports and services. A majority are also working to incorporate the principles of consumer direction into their LTC systems. The following sections provide information about Grantees' initiatives in each of the six focus areas, broken into several categories.

3.1 CONSUMER DIRECTION AND CONTROL

A major goal of the Systems Change Grants Program is to assist states in creating LTC systems that give consumers maximum control over their services. Grantees in 41 states are involved in initiatives to incorporate the principles of consumer direction into their LTC systems. As shown in Exhibit 3, initiatives in this focus area are grouped into five categories:

- administrative rules and regulations, including activities to incorporate principles of consumer direction into agency mission statements and policy guidelines;
- legislation and executive orders;
- pilot projects or model programs; and
- training and education for consumers, families, and providers.

Exhibit 2. States Working in Each Area of Systems Change

State*	Total Areas for Each State	Consumer Direction and Control	Access to Long Term Care Support Services	Budget and Reimbursement	Service Creation and/or Modification	Long Term Care Workforce	Quality Management
Alabama	4	•	•	•	•		
Alaska	6	•	•	•	•	•	
Arkansas	6	•	•	•	•	•	•
California	3	•	•			•	
Colorado	5	•	•	•	•		•
Connecticut	4	•	•		•	•	
Delaware	5	•	•	•	•	•	
District of Columbia	6	•	•	•	•	•	•
Florida	3	•	•			•	
Georgia	5	•	•	•	•	•	
Guam	6	•	•	•	•	•	•
Hawaii	4	•	•	•	•		•
Idaho	5	•	•	•	•	•	
Illinois	4	•	•	•		•	
Indiana	6	•	•	•	•	•	•
Iowa	5	•	•	•	•	•	
Kansas	6	•	•	•	•	•	•
Kentucky	3		•			•	•
Louisiana	6	•	•	•	•	•	•
Maine	6	•	•	•	•	•	•
Maryland	6	•	•	•	•	•	•
Massachusetts	6	•	•	•	•	•	•
Michigan	6	•	•	•	•	•	•
Minnesota	5	•	•		•	•	•
Mississippi	4	•	•		•		•
Missouri	4		•	•	•		
Montana	3		•	•		•	
Nebraska	3	•	•		•		
Nevada	5		•	•	•	•	•
New Hampshire	5	•	•	•	•	•	
New Jersey	2		•			•	
New Mexico	0**						
New York	2		•	•			
North Carolina	6	•	•	•	•	•	•
North Dakota	1		•				
Northern Mariana Islands	4		•	•	•	•	
Ohio	4	•	•		•		•
Oklahoma	6	•	•	•	•	•	•
Oregon	5	•	•	•	•	•	
Pennsylvania	4	•	•	•		•	
Rhode Island	5	•	•	•	•	•	
South Carolina	5	•	•	•	•	•	
Tennessee	2	•	•				
Texas	4	•	•	•		•	
Utah	3	•	•		•	•	
Vermont	6	•	•	•	•	•	•
Virginia	4	•	•			•	•
Washington	6	•	•	•	•	•	•
West Virginia	6	•	•	•	•	•	•
Wisconsin	4	•	•	•		•	
Wyoming	2		•				•
Total		**41**	**50**	**36**	**36**	**39**	**24**

*Every state except Arizona and South Dakota received a grant in FY 2001 and FY 2002. These two states received a grant in FY 2003.

**New Mexico reported that no activities were being pursued during the reporting period because the grant was in the process of being transferred to another department.

Exhibit 3. 41 States with Initiatives to Incorporate Principles of Consumer Direction into Policies, Regulations and Services

State	Administrative Rules & Regulations	Legislation & Executive Orders	Pilot Projects or Model Programs	Education and Outreach
Alabama	•			•
Alaska	•		•	
Arkansas	•		•	•
California	•			•
Colorado		•		•
Connecticut				•
Delaware	•	•		•
District of Columbia	•			
Florida		•	•	
Georgia	•		•	•
Guam	•	•		
Hawaii	•			•
Idaho				•
Illinois		•		•
Indiana	•	•		
Iowa	•	•		
Kansas	•		•	
Louisiana			•	
Maine	•			
Maryland				•
Massachusetts	•		•	•
Michigan	•			•
Minnesota	•			
Mississippi	•			•
Nebraska		•		
New Hampshire	•		•	•
North Carolina	•		•	•
Ohio	•			•
Oklahoma	•		•	
Oregon	•			•
Pennsylvania	•			
Rhode Island	•			•
South Carolina	•		•	•
Tennessee				•
Texas				•
Utah	•			
Vermont				•
Virginia				•
Washington	•			•
West Virginia	•		•	•
Wisconsin				•
Total	**28**	**8**	**12**	**27**

Exhibit 3 shows the 41 states with grant activities in each of the four categories. Grantees' activities are focused primarily on changing administrative rules and regulations and providing education and outreach to consumers. Fewer Grantees are conducting pilot projects, pursuing legislative changes or executive orders, or incorporating consumer direction into waiver programs.

In the following subsections, we present examples of Grantee activities in each of the five categories to illustrate the type and range of initiatives Grantees are undertaking.

3.1.1 Administrative Rules, Regulations, and Policies

One method for moving toward a consumer-directed community LTC system is to incorporate the principle of consumer direction into agency mission statements, policy guidelines, rules, and regulations. As shown in Exhibit 3, Grantees in 28 states are undertaking activities in this category. Examples include

- **Indiana (RC, CPASS)** incorporated consumer-directed care into draft policy for the Indiana Bureau of Aging and In-Home Services, and has also incorporated the principle of consumer direction into a new draft state rule on services for the aged and disabled.
- **Nebraska (RC)** reviewed regulations across the health and human services system and worked to revise the personal assistance service regulations to incorporate principles of consumer direction. As a result, the State developed a statute allowing consumers the right to choose among the array of available services.
- **North Carolina (RC)** collaborated with other divisions within the State's Department of Health and Human Services to establish a set of guiding principles that promote consumer direction and choice.[a]
- **Oklahoma (CPASS)** adopted guiding principles for consumer-directed personal assistance services and supports (PASS), mandating that the design of the CD-PASS program model will support individual empowerment, enhance personal independence, and realize the independent living principle in service delivery.

3.1.2 Legislation and Executive Orders

During the reporting period, Grantees in eight states engaged in a range of activities to assure that legislation or executive orders supported consumer-directed services. Examples include

- **Indiana (RC, CPASS)** provided assistance in the drafting of legislation passed in the 2003 session mandating that consumer-directed care be available in at least one waiver program by July 1, 2004.

[a]Where interagency collaboration and memoranda of understanding are discussed throughout Sections 3.1 through 3.6, please refer to Appendix B for a complete list of Grantee lead agencies.

- **Iowa (RC)** incorporated consumer direction into the Mental Health and Developmental Disabilities Commission recommendations for service system redesign to the Iowa legislature in December, 2003.

3.1.3 Consumer-Directed Pilots and Model Programs

Grantees in 12 states are implementing consumer-directed pilot projects to assess the feasibility of large-scale, consumer-directed programs. Examples follow.

- **Louisiana (RC)** worked to add a consumer direction component to Louisiana's New Opportunities Waiver (NOW) and is planning to initiate a consumer-directed pilot project under the waiver for persons with developmental disabilities. During the reporting period, approximately 50 persons receiving NOW services had been recruited to participate in the pilot. A consumer satisfaction tool to evaluate the pilot has been developed, and the procurement process for securing a fiscal agent for the pilot is underway.
- **South Carolina (RC)** developed *SC Choice* policies and procedures and integrated them into the Community Long Term Care Program. Financial management service hiring packets and other materials were developed in preparation for the implementation of the *SC Choice* pilot program. The first pilot was implemented in September 2003.
- **West Virginia (CPASS)** has developed the framework for a consumer-directed services model within its Aged & Disabled waiver program. Once implemented, the consumer directed services will be available to approximately 5,400 individuals statewide.

3.1.4 Education and Outreach

For consumer direction to be a viable service option, both consumers and providers need training to make it work. Consumers need the skills necessary to direct their own care. Providers and agency personnel need education and training to meet the needs of clients who wish to direct their own care. Grantees in 27 states described education initiatives to teach consumers and providers about consumer-directed community service options. For example, Grantees are developing informational materials, websites, training materials, and curriculums. They are also conducting consumer outreach activities to encourage them to consider consumer-directed supports and services. For example:

Education

- **Colorado (CPASS)** has developed and implemented a consumer training curriculum and related materials as part of its initiative to employ principles of consumer-direction in the provision of services.
- **Hawaii (CPASS)** has begun coordinating statewide information dissemination and training about a newly authorized consumer-directed personal assistance services option in its HCBS waiver program.
- **Massachusetts (NFT)** is developing a discharge protocol outlining agencies' responsibilities for providing information on consumer direction and control to persons being discharged from nursing facilities.
- **Michigan (RC),** in its effort to establish processes that ensure consumer control over service and supports, produced training and education materials, including anti-stigma materials and micro-enterprise materials, for a model in which consumers and family members collectively assume responsibility for their outcomes and take control of the resources needed to achieve their goals.
- **South Carolina (RC)** has been working with the Spartanburg Area Mental Health Center's Director for Children, Adolescents, and Families to identify strategies for integrating more consumer choice and control into State-funded mental health services. The Grantee developed educational and outreach materials about consumer choice and control for staff, providers, and consumers. The Grantee also developed instructional packets on hiring workers and financial management services for use in the consumer direction pilot project. In addition, the Grantee developed a training session on consumer-directed care planning to certify mental health staff as information resource specialists.
- **Virginia (RC)** developed train-the-trainer materials to educate families, consumers, and providers about consumer direction.
- **Washington (RC)** implemented consumer-directed care education and training for elderly persons and adults with disabilities. The Grantee has awarded 25 small grants to local councils in 33 counties throughout the State to provide education and training on consumer-directed services.

Outreach

- **Delaware (NFT-ILP)** assisted in the establishment of a peer support group for consumers who achieved their goal

of living in their own community residence. The goal of the support group is to provide consumers an opportunity to communicate with persons in similar circumstances about efforts to direct their services.

- **Georgia (RC)** is developing peer support projects for people with mental illness, developmental disabilities, and physical disabilities, as well as elderly persons in nursing homes. The Grantee has developed a curriculum for mental health peer support specialists working in hospitals to encourage consumers who want to direct their own care.
- **Washington (NFT)** has implemented a new standardized comprehensive assessment tool, CARE, which relies on participation and input from the consumer. Within the parameters of the assessment tool, clients have the opportunity to specify the details of their individualized service plan, including who will provide personal assistance services, and where services will be provided.

3.2 ACCESS TO LONG TERM CARE SERVICES AND SUPPORTS

Ensuring access to the full range of services and supports for persons with disabilities of all ages is a critical component of LTC systems rebalancing. Grantees in all but one state reported progress on activities to provide or increase access to new or existing services and supports. As shown in Exhibit 4, initiatives to improve access are grouped into six broad categories:

- integrated access to long term care systems,
- streamlined financial and functional eligibility determinations,
- expanded eligibility,
- nursing facility resident transition and diversion,
- informed consumer choice, and
- other related activities.

The majority of Grantees are working to integrate access to LTC systems, transitioning individuals, ensuring informed consumer choice, and by addressing other services and supports including housing, home modification, and transportation. Grantees in 25 states are engaged in efforts to streamline or expand eligibility for Medicaid state plan or HCBS waiver services. In the following subsections, we present examples of Grantee activities in each of the six categories to illustrate the type and range of initiatives they are undertaking.

Exhibit 4. 50 States with Initiatives to Improve Access to Long Term Care Services

State	Integrated LTC Systems	Streamlined Eligibility Determinations	Expanded Eligibility	Nursing Facility Resident Transition*	Informed Consumer Choice	Other**
Alabama	•			•	•	•
Alaska		•		•	•	•
Arkansas	•	•		•	•	•
California				•	•	•
Colorado	•	•		•	•	•
Connecticut	•			•	•	
Delaware	•		•	•	•	•
District of Columbia	•	•	•	•	•	•
Florida	•			•	•	•
Georgia	•			•		•
Guam	•	•		•	•	
Hawaii	•	•			•	•
Idaho	•		•	•	•	•
Illinois	•	•		•	•	•
Indiana		•	•	•	•	
Iowa	•			•	•	
Kansas			•	•	•	
Kentucky				•	•	•
Louisiana	•	•	•	•	•	•
Maine						•
Maryland				•	•	
Massachusetts	•	•	•	•	•	•
Michigan	•	•		•	•	•
Minnesota	•			•	•	•
Mississippi				•		•
Missouri	•	•		•	•	•
Montana					•	•
Nebraska	•			•	•	
Nevada				•	•	•
New Hampshire	•	•		•	•	•
New Jersey	•			•		•
New York				•		
North Carolina	•		•	•	•	
North Dakota					•	
Northern Mariana Islands	•				•	
Ohio	•			•	•	
Oklahoma		•	•	•	•	•
Oregon					•	•
Pennsylvania	•	•	•	•	•	•
Rhode Island	•			•	•	•
South Carolina	•			•	•	•
Tennessee	•		•	•	•	•
Texas	•			•	•	•
Utah	•			•	•	•
Vermont	•	•	•	•	•	•
Virginia					•	•
Washington		•	•	•	•	•
West Virginia		•	•	•	•	•
Wisconsin	•	•	•	•	•	•
Wyoming		•		•	•	•
Total	**32**	**20**	**16**	**43**	**45**	**38**

*NFT transition and diversion activities encompass a range of activities including increasing housing availability and accessibility, developing peer support networks, and developing outreach materials and conducting outreach.

**This category includes the areas of community education, housing, home modifications, assistive technology and transportation.

3.2.1 Integrated Access to Long Term Care Systems

Grantees in 32 states described efforts to improve access by integrating information sources for multiple LTC services and supports, primarily by creating single-point-of-entry systems; websites and toll-free phone lines; and dedicated information, referral, and assistance staff positions. Several states reported using existing networks of Area Agencies on Aging (AAAs) or Centers for Independent Living (CILs) to serve as an entry point for LTC services and supports programs. A few states conducted research and feasibility studies to assess the feasibility of creating a single-point-of-entry system or to address specific access issues. In a few states, grant staff are also supporting the development of AoA grant-funded Aging and Disability Resource Centers (ADRCs). Examples include

- **Alabama (RC)** collaborated with community partners to develop the *211 Connects Program*, an information clearinghouse that serves as a central point of LTC information and referral.
- **Alabama (RC)**, **North Carolina (NFT)**, and **Vermont (RC)** are using their grants to support studies and/or assessments to determine whether a single-point-of-entry system for LTC services is feasible.
- **Arkansas (RC, CPASS, NFT)** developed a statewide website (http://www.argetcare.org/) to serve as a single point of entry for Divisions of Developmental Disabilities and Aging and Adult Services. The website includes service definitions, a self-assessment tool, a provider directory by geographic area, and links to provider websites.
- **Connecticut (NFT)** established a single point of entry to the transition system through independent living centers (ILCs), which help callers obtain services. A toll-free phone number for the ILCs is listed on all transition materials.
- **Hawaii (RC)** developed a single-entry-point website (http://www.realchoices.org/) with contact information for service providers across the state. The website also has information about resources to address needs in eight major life areas.
- **Minnesota (RC)** created the Disability LinkAge Line—a free information, referral, and assistance service—to make it easier for people with disabilities to connect with community services and supports, and joined it with the Housing Link and Senior LinkAge Line to create a statewide comprehensive information referral and assistance system using a single database and website (found at

(http://www.minnesotahelp.info/en/mn/cgi-bin/location.asp).

- **South Carolina (RC)** is expanding the scope of *SC Access*—an information and assistance system—to include coordination of LTC services and supports at the local level. The State has trained 10 information and referral specialists in the statewide Aging Services Network to provide consumers with comprehensive information about the services available through *SC Access.* A pilot Aging and Disability Resource Center will be designed and tested to provide a single point of entry to services for older adults and persons with physical disabilities.
- **Texas (RC)** has been testing the use of system "navigators"—individuals who assist consumers to access services. Two models are being tested, one in which navigators are co-located at an agency that is serving as a single point of access to community services and the other in which navigators are located in different agencies across multiple points of access. The Grantee has trained 12 system navigators who have assisted 175 consumers.

3.2.2 Streamlined Financial or Functional Eligibility Determinations

Grantees in 20 states described initiatives to administratively streamline financial and/or functional eligibility determinations for Medicaid state plan and HCBS waiver programs. Activities included developing methods to expedite financial and functional eligibility determinations, such as creating standardized and uniform functional assessment tools, and streamlining level of care determinations. Examples include

Financial

- **Arkansas (RC)** designed a "Fast Track" project to assure that programmatic and financial eligibility determinations are made within 7 days of application for two Medicaid waiver programs: ElderChoices (age 65+) and Alternatives (adults age 21 to 64 with physical disabilities). The State also developed a standardized form to establish eligibility for both nursing facilities and HCBS waivers.
- The **District of Columbia (RC, CPASS)** has established a process to expedite financial eligibility determinations for waiver services.

Functional

- **Alaska (NFT)** supported implementation of a "Fast Track" level of care authorization system for HCBS waiver programs for individuals transitioning from nursing homes.

- **Louisiana (NFT)** developed a uniform LTC assessment tool for all State LTC services.
- **Massachusetts (RC)** developed a uniform functional assessment tool and process to determine the amount of service funding individuals will receive. It will be tested in a pilot project to increase the quality of life and independence of participants through flexible service funding.
- **Oklahoma (RC)** revised the Oklahoma Administrative Code to clarify Uniform Comprehensive Assessment Tool (UCAT) criteria used for nursing facility level of care determination. The Grantee removed the UCAT health assessment domain score as the sole criterion for establishing consumer need, but retained the health assessment as part of a combined assessment of need.
- **Washington (NFT, RC)** developed a comprehensive assessment tool (described in Section 3.1.4) and a cross-systems case management model that serve as the foundation for eligibility determination and assessment across all disability populations.
- **Wisconsin (RC)** is implementing an adult LTC functional eligibility screen statewide and developing functional eligibility screens for children and persons with mental illness.

3.2.3 Expanded Eligibility

Grantees described efforts to expand eligibility for Medicaid state plan or HCBS waiver programs for persons with disabilities. Several states worked to develop new waiver programs or to add a new target population to an existing HCBS waiver. Other states increased access through changes in financial eligibility criteria. Examples include

- The **District of Columbia (RC, CPASS)** worked to increase the income eligibility standard for the waiver program to 300 percent of the Supplemental Security Income (SSI) eligibility threshold.
- **Idaho (RC)** began an economic analysis of the current system to identify potential funding strategies and options for leveraging existing funds. The Grantee is also developing a database to support cost-benefit analyses of various system configurations.
- **Wisconsin (RC)** is analyzing the possibility of developing an HCBS waiver program for persons with serious mental illness who are in nursing homes.

3.2.4 Nursing Facility Resident Transition and Diversion

Exhibit 5 presents transition information for the current reporting period October 1, 2002, to September 30, 2003. Twenty-five Grantees in 23 states reported successfully transitioning a combined total of 1,268 consumers to community settings and diverting 42 consumers from entering nursing facilities or other institutions. Years One and Two combined have yielded 1,638 transitions and 48 diversions. The majority of NFT Grantees are focused on establishing transition processes and a transition system, rather than diversion activities.

In addition, 22 Grantees in 21 states provided information about transitioning to 5,406 people. Nebraska provided transition information to 500,000 people by using a communication/ marketing campaign in the three pilot AAA territories that span the major population centers of eastern Nebraska, including Omaha, Lincoln, and Norfolk. Most Grantees used multiple methods for distributing information to the community, but personal contact and communication through a social worker were the most widely used.

Grantees in 43 states described a range of nursing facility transition and diversion initiatives and strategies. The majority of these are NFT Grantees, but some states have RC and/or CPASS Grantees that are also supporting NFT efforts. State program and ILP Grantees reported a wide range of approaches to transition and/or divert individuals:

- Creating transition assessment tools;
- Developing outreach materials and conducting outreach;
- Providing workshops and training for hospital staff and other community providers involved in the transition and diversion process;
- Amending waiver programs to give priority for waiver slots to those able to transition;
- Developing intervention plans and protocols;
- Increasing housing availability and accessibility through vouchers (Section 8 and Project Access), home modifications, and other means;
- Establishing peer support, local community, and service provider networks (e.g., CILs and AAAs); and
- Providing small grants to consumers for transition costs.

Exhibit 5. Individuals Transitioned to Community Settings and Methods Used to Disseminate Information, by State

State (Grantee)	Number Transitioned√	Number Diverted√	Number Who Received Information	Methods of Information Dissemination					
				Personal Contact	Social Worker	Facility Staff	Brochures	Toll-Free #s	Other*
Alabama	n/a	0	0	•	•				
Alabama (ILP)	13	n/a	21	•	•	•	•		
Alaska	12	n/a	50	•	•	•	•		•
Arkansas	n/a	0	0						
California (ILP)	20	1	275	•	•	•	•	•	•
Colorado	93	n/a	417	•	•	•	•		
Connecticut	31	n/a	100	•	•	•	•	•	•
Delaware	0	n/a	199	•	•	•	•		•
Delaware (ILP)	5	n/a	13	•	•	•	•	•	
Georgia	8	n/a	0	•	•	•	•	•	
Georgia (ILP)	20	8	100	•	•	•	•	•	•
Indiana	0	0	0	•	•	•	•		•
Louisiana	44	n/a	0	•	•	•	•	•	•
Maryland	n/a	n/a	1,083	•	•	•	•	•	•
Maryland (ILP)	0	n/a	0						
Massachusetts	6	n/a	22	•	•	•	•		•
Michigan	146	0	181	•	•	•	•	•	•
Minnesota (ILP)	43	n/a	1,777						
Nebraska	147	n/a	500,000†	•	•	•	•		•
New Hampshire	1	0	15	•	•	•	•		•
New Jersey	98	n/a	500	•	•	•	•	•	
New Jersey (ILP)	11	n/a	22						
North Carolina	13	n/a	17	•	•	•	•	•	
Ohio	n/a	n/a	0						
Rhode Island	16	n/a	47	•	•	•			•
South Carolina	2	n/a	15	•	•	•	•		•
Texas (ILP)	n/a	n/a	0						
Utah (ILP)	28	n/a	45	•		•			
Washington	209	n/a	0	•	•	•			•
West Virginia	15	33	392	•	•	•	•	•	•
Wisconsin	127	0	50	•	•				•
Wisconsin (ILP)	69	n/a	0	•	•	•	•	•	•
Wyoming	13	n/a	65	•	•	•	•	•	•
Total	**1,268**	**42**	**505,406**	**27**	**26**	**25**	**22**	**13**	**19**
Percent	**—**	**—**	—	***75%***	***72%***	***69%***	***61%***	***36%***	***53%***

*This category includes, but is not limited to, presentations (7), advocacy groups (3), medical professionals (2), facility staff (3), ombudsmen (3), website (2), waiver program staff (2). Several Grantees reported using multiple methods of dissemination under the "other" category.

†The 500,000 figure is based on published radio market share and newspaper readership statements.

√n/a indicates that the Grantee did not plan to transition or divert individuals during the reporting period. Texas ILP is the only grant that is not planning to divert or transition individuals, but rather to support the identification of individuals seeking to transition to community; to provide training targeted to state agency staff, consumers, advocates, and private service providers to address transition barriers; and to contribute to the state's long term care infrastructure.

Several examples follow.

NFT Grantees

- **Alabama (NFT)** has been evaluating the costs and outcomes of its hospital-to-home transition program, by comparing two groups of individuals enrolled in the Waiver program: (1) patients returning to home care, and (2) patients entering a nursing facility upon discharge. The State has been working on plans for additional analysis to determine both Medicaid and Medicare costs during the year following hospital discharge. The Grantee also produced a workbook to train discharge coordinators and case managers in dementia caregiving techniques.
- **Alabama (NFT-ILP)** received 57 referrals and transitioned 19 individuals out of nursing homes through its *Partnerships through Independence* program. The Grantee trained 10 Peer Supporters who were paired with transition candidates to follow them through the pre- and post-transition period. The Grantee has also been tracking program outcomes using a computerized management information system that has consumer data, including the amount of time required to transition individuals into the community. Program staff also plan to ask consumers to evaluate the effectiveness of the program.
- **California (NFT-ILP)** has transitioned 20 individuals, diverted one individual, initiated a Peer Support Mentor Program, and trained potential mentors. The Grantee coordinated with the State to develop new assessment policies and procedures to assure that individuals who are transitioning have personal assistants available when they transition. The Grantee did report problems with conducting outreach to hospital social workers, discharge planners, nursing homes, and family members, and others throughout the pilot area due to small numbers of staff in a large geographic area.
- **Colorado (NFT)** developed and disseminated NFT materials to local media, stakeholders, and nursing facilities; provided technical assistance about the transition process to the State's 10 ILCs; conducted outreach and education activities; informed 417 individuals of their right to choose home and community services; and transitioned 93 individuals. The Grantee also designed a communication board and picture book about nursing facility transition for individuals with verbal communication impairments.
- **Connecticut (NFT)** conducted a survey to inform the design of an outreach pilot for nursing home residents. The

Grantee initiated and evaluated the pilot program, and modified it for statewide implementation. The Grantee also published a self-assessment tool and a step-by-step transition guide. The Grantee also worked with the State's Medicaid Infrastructure Grant (MIG) to help transitioned individuals find work.

- **Delaware (NFT-ILP)** developed and conducted pre-transition education workshops and a developed a manual for ILCs to conduct additional workshops; acquired a mini-grant to assist consumers with transition costs; and transitioned five consumers.
- **Indiana (NFT)** amended waiver policies to give priority for waiver slots to individuals eligible for diversion or transition from a nursing facility and diverted or transitioned more than 800 people.
- **Massachusetts (NFT)** signed an interagency agreement with the Division of Medical Assistance (DMA) to share data on consumer service costs for individuals transitioning from nursing facilities. The Grantee is maintaining a database to track transition costs and other data (e.g., consumer satisfaction).
- **Michigan (NFT)** developed a care planning model for transitions that includes both services and housing options, and transitioned 146 individuals. The Grantee is planning to conduct a cost-benefit analysis and outcomes evaluation. For the outcome evaluation, the State plans to use the Minimum Data Set—Resident Assessment Instrument, the Minimum Data Set—Home Care Instrument, and other secondary data sets to measure outcomes for individuals who have transitioned. For the cost benefit analysis, the State plans to analyze participants using Minimum Data Set—Resource Utilization Groups.
- **Nebraska (NFT)** has developed partnerships with nursing facility staff and other key stakeholders to facilitate the transition process, and has transitioned 147 nursing facility residents. The State also established a program called *Waiver While Waiting* to enable individuals at risk for nursing home placement to receive services while waiting for the waiver eligibility determination.
- **Wisconsin (NFT)** amended its HCBS Waiver for elderly persons and persons with physical disabilities to include transition services; transitioned 127 individuals; and initiated three housing projects. The first project included the development of a process to obtain interagency agreements to convert senior apartments to assisted living. The second project assisted 73 people with home repairs

and modifications, and the third project created a cooperative for elderly housing in a rural area.

- **Wisconsin (NFT-ILP)** provided peer support for individuals transitioning from nursing facilities and assisted in transitioning 110 people. The Coalition of Wisconsin Independent Living Centers has committed to having ILC staff provide transition services beyond the grant period.

As stated above, several states with RC and CPASS grants (some with and some without accompanying NFT grants) supported transition and diversion efforts. Many had activities to identify potential candidates, increase the availability and affordability of housing for persons transitioning, and increase community transition supports. Examples follow.

Real Choice and CPASS Grantees

- **Delaware (RC)** implemented a screening and evaluation process for individuals in the State's intermediate care facilities for the mentally retarded (ICF/MR) to identify transitioning individuals who needed assistive technology and home modifications. During the reporting period, they screened over 200 consumers.
- **Illinois (RC)** explored innovative housing options for individuals with developmental disabilities who were interested in transitioning from group homes or institutional settings, to other community settings, including an option for home ownership. The home ownership program uses Fannie Mae's *HomeChoice* mortgage program for financing, and grants to assist with down payments and closing costs. During the reporting period, 45 consumers received grants to help them transition from institutional settings or to remain in the community; 6 more were transitioned from nursing facilities.
- **Maryland (RC)** helped divert 104 hospital patients from nursing home placement (or assured that their rehabilitation stay was temporary) and assisted 113 nursing facility residents to transition.
- **Oklahoma (RC)** evaluated nursing facility transition support infrastructure needs to gain detailed knowledge of transition service requirements and costs. The Grantee then developed a pilot to secure transition services for 50 consumers. The Grantee also collaborated with other State agencies to develop a policy allowing transition case management, environmental modifications, and durable medical equipment to be reimbursed through the State's HCBS waiver program, assuring that these services will be available after the grant ends.

- **Vermont (RC)** expanded the State's Options Counseling Program to provide consumers applying for nursing home admission (from the hospital or community) with information about home and community service options, assistance in obtaining these services, and encouragement to exercise choice.
- **Washington (RC)** transitioned 130 individuals from a state psychiatric hospital through a cross-agency transition initiative funded by the grant. The cooperative effort of the Aging and Disability Services Administration and the Mental Health Division identified candidates, planned for their discharge, and transitioned these long-time residents with complex needs to residential settings. Community stakeholders and the hospital transition team also finalized a new policy regarding early treatment plans that addressed discharge planning and community provider involvement for discharge of patients from state hospital units serving individuals with developmental disabilities.

3.2.5 Informed Consumer Choice through Information Systems and Other Mechanisms

Grantees in 45 states reported activities to increase informed consumer choice by providing outreach and education related to LTC services and supports, by building infrastructure, and/or making improvements to information systems. The majority of Grantees are implementing specific activities to inform consumers about their options, such as providing education and training, peer support, and outreach. A few states are engaged in developing and improving information systems. Examples include

Mechanisms to Increase Informed Consumer Choice

- **California (NFT-ILP)** established weekly transition peer support meetings that included educational efforts and individualized options counseling.
- **Florida (RC)** helped establish the State's accessibility policy for persons with disabilities to provide equal access to government information and information systems. The Grantee received a state leadership award for work in this area. The Grantee also completed a pilot program to determine costs and benefits of a statewide automated and accessible benefits screening program for professionals and consumers, but the program was not funded by the legislature and was put on hold.
- **Guam (CPASS)** conducted a training about assistive technology options and benefits for 100 individuals with disabilities, advocates, and service providers.

- **Missouri (RC)** developed a training curriculum, *Informed Choice*, to increase awareness among guardians and those who work with them about consumer choice. Using a train-the-trainer approach, the Grantee completed a pilot program using the curriculum and has begun phase-in of statewide *Informed Choice* training for judges, public administrators, attorneys, and others involved with guardianship activities.
- **Montana (RC)** formed a coalition, *HomeChoice*, to coordinate housing services for persons with all types of disabilities. The Grantee also developed outreach materials, conducted 18 presentations, and trained 360 persons on accessible home ownership.
- **Vermont (RC)** implemented a counseling program to discuss placement options to ensure that consumers applying for admission to a nursing home are informed about all of their available options. The Grantee terminated the program after a year, because the program did not lead to an increase in the number of individuals receiving home and community services.

Information Systems

- **Arkansas (RC),** by pooling resources with the Robert Wood Johnson Foundation, helped plan and implement a web-based information system—South Arkansas Health Education, Living and Life Options (http://www.sa-hello.org/)—that consumers can use to learn about and locate services in two counties.
- **Delaware (RC)** developed a website (http://www.dati.org/home.html) that provides comprehensive information on assistive technology (AT), an equipment exchange program, online access to the statewide AT inventory for demonstration and short-term loan, and searchable databases of funding supports and AT providers.
- **Nevada (CPASS)** used grant funds to develop a new data system in the Office of Disability Services to better track and serve all PASS clients. The system assists in care planning, screening for other resources, and managing program resources to optimize the number of individuals served.

3.2.6 Other Initiatives to Increase Access

Grantees described additional efforts to increase access to long-term supports and services, primarily through community education activities and improving access to housing, home

modification services, assistive technology, and transportation. Examples include

Community Education

- **Alaska (RC)** convened a disability policy summit for advocacy boards and the state legislature to ensure that a planning, capacity building, monitoring, and advocacy structure was in place and that people with disabilities participated in systems change efforts.
- **Idaho (RC)** implemented a statewide education campaign to reduce stigma pertaining to disability, long-term illness, and older adults. The campaign included a five-segment novella for Spanish radio, 15,000 copies of a brochure, creation and dissemination of a poster, several 30-second television advertisements and one radio advertisement, featuring the State's First Lady. By building strong partnerships with groups and organizations to better understand what existing resources are available and to help obtain new resources, the Grantee received approximately $600,000 in free advertising associated with the anti-stigma campaign.
- **New Hampshire (RC)** cosponsored gubernatorial and senate forums with AARP to educate candidates on issues affecting home and community services for older adults and persons with disabilities. The Grantee also conducted three educational sessions for over 300 legislators on disability policy, financing home and community services, and workforce issues.

Housing

- **Alabama (RC)** established seven, three-bed residential homes and provided training to agency and state psychiatric hospital staff on person-centered discharge planning.
- **Kentucky (RC)** required use of Universal Design procedures in all housing development projects using majority funding from the state housing finance agency. The Grantee published a Universal Design Handbook and posted it on the Kentucky Housing Corporation website.
- **Louisiana (RC)** reported that Grantee efforts contributed to the passing of legislation to establish a State Housing Trust Fund.
- **Maryland (NFT)** established a housing coordinator staff position to develop and maintain a statewide affordable/ accessible housing registry; to liaise with state agencies, local public housing authorities, and other housing stakeholders; and to develop informational material on

affordable and accessible housing for individuals with disabilities.

- **Montana (RC)** formed a *HomeChoice* Coalition that trained approximately 360 persons about accessible home ownership. At the time of the report, 47 new housing opportunities were being developed; 22 of these were being built to meet Universal Design standards.
- **New Jersey (NFT)** signed an interagency agreement with the Department of Community Affairs and Human Services to increase the availability of and financial assistance for housing through U.S. Department of Housing and Urban Development (HUD) Project Access vouchers.
- **Oregon (RC)** collaborated with the Oregon Homeless Policy Team to increase housing options for people disabled by mental illness, in an effort to increase access to rent subsidies, facilitate provision of one-time housing assistance for consumers transitioning to the community, and increase access to non-Medicaid benefits. The Grantee also implemented a housing fund that has awarded small grants to 27 consumers to help them retain or obtain community integration. The Grantee's goal is to eventually serve 500 individuals.
- **Tennessee (RC)** has hired local community consumer housing specialists to help complete the *Housing Within Reach* website (http://www.housingwithinreach.org/). This website provides information about housing options and other housing-related issues. Consumer housing specialists are also disseminating housing information at drop-in-centers, community meetings, and housing-related state meetings.
- **Washington (NFT)** contracted with a Center for Independent Living to represent and promote the interests of nursing facility residents with the housing authority and other housing entities. The Grantee transitioned over 200 people including 21 individuals who used Project Access housing vouchers.

Home Modification and Assistive Technology

- **Colorado (RC) and West Virginia (CPASS)** staff are considering ways to improve the administration and provision of home modifications.
- **Delaware (RC)** developed an Assistive Technology (AT) Low Interest Loan Program that has been seeded with $1.3 million in federal funds. The Grantee also developed and implemented an AT training curriculum for case managers and has established an AT screening protocol and follow-up process as mentioned in Section 3.2.4. In addition, the

Grantee conducted surveys of consumers and state agencies about AT access and use, and developed an AT Legislative Policy Committee that issued a report to the Legislature. The Grantee has also developed a protocol and system for home modification evaluations for persons with developmental disabilities.

- **Illinois (RC)** is working with the Housing Development Authority to create a list of home modification resources to guide consumers to available funding. The Grantee is also working to ensure that customers receive accurate assessments and rapid responses for home modifications.

Transportation

- **Maine (RC)** participated in a Department of Transportation work group to work on the transportation recommendations made in Maine's *Roadmap for Change* (a cross-agency LTC planning report), and to coordinate the grant's initiatives to design and implement at least two transportation demonstration projects that include flexible transportation budgets, detailed pricing options, and ride share.
- **Montana (RC)** formed the Western Transportation Partnership, a broad coalition of stakeholders, to address transportation goals. A transportation advocate has been hired and two demonstration communities have been selected for the project: Helena and Missoula.
- **Northern Mariana Islands (RC)** supported the Saipan and Rota Call-A-Ride initiatives to provide transportation services for persons with disabilities by producing bumper stickers and information leaflets/flyers.

3.3 STATE BUDGETING AND REIMBURSEMENT

A primary goal of the Systems Change grant program is to help states redesign their LTC services to be more responsive to consumers' desire to receive home and community services. In response, many states are modifying existing fiscal structures to assure that home and community services are delivered efficiently and cost effectively.

Grantees in 38 states are considering or developing budget or reimbursement initiatives to make their LTC systems more consumer-oriented, accessible, efficient, and cost effective. As shown in Exhibit 6, efforts are grouped into four categories:

- individualized budgeting,
- payment rates and methodologies,

Exhibit 6. 36 States with Budget and Reimbursement Initiatives

State	Individualized Budgeting	Payment Rates and Methodologies	Money Follows the Person	Consolidated Budget
Alabama		●		
Alaska	●	●		
Arkansas	●	●	●	
Colorado	●	●		
Delaware	●	●	●	●
District of Columbia	●	●		
Georgia	●			
Guam	●			
Hawaii	●	●		
Idaho		●		
Illinois		●		
Indiana	●	●	●	●
Iowa		●		
Kansas			●	
Louisiana	●			
Maine	●			
Maryland		●	●	
Massachusetts	●	●	●	
Michigan	●	●	●	
Missouri	●			
Montana		●		
Nevada	●	●	●	
New Hampshire	●	●	●	
New York	●		●	
North Carolina	●	●		
Northern Mariana Islands		●		
Oklahoma	●	●		●
Oregon	●			
Pennsylvania	●	●		
Rhode Island		●		
South Carolina	●	●	●	
Texas			●	
Vermont	●	●	●	●
Washington	●	●		●
West Virginia	●	●		
Wisconsin	●	●	●	
Total	**26**	**27**	**14**	**5**

- Money Follows the Person, and
- consolidated budgets.

The majority of these states have initiatives focusing on individualized budgeting and initiatives to reform payment rates and related methodologies. Over a third of the states are working on Money Follows the Person initiatives. Only five states have initiatives focusing on consolidated budgets. In the following subsections, we present examples of Grantee activities in each of the four categories to illustrate the type and range of initiatives they are undertaking.

3.3.1 Individualized Budgets

The amount of control consumers have over their services varies across states. In some states, consumers have the opportunity to express their service preferences; in others, they can choose which services they want; and in some, they can choose to manage a personal budget to purchase the services they want. In the area of individualized budgeting, Grantees are developing pilot and demonstration projects, waiver-related initiatives, and education initiatives. Examples include

Pilots and Demonstrations

- **Massachusetts (RC)** is conducting a pilot project using a flexible consumer-directed option with individual budgets based on participants' functional level.
- **Oklahoma (CPASS)** is developing the infrastructure to allow consumers to set reimbursement rates for providers within State-set parameters and to determine when and how services will be delivered.
- **Oregon (RC)** is operating a mental health brokerage demonstration project for up to 25 mental health service participants, which gives them control over a $3,000 budget for up to 18 months. The funds can be used to purchase products and services to aid in their recovery.

Waiver-Related Initiatives

- **Hawaii (CPASS)** has been exploring and demonstrating flexibility in budgeting as well as documenting the success of an Independence Plus/Cash and Counseling model. This Grantee is working to provide greater consumer flexibility, control, and choice in managing an allocated budget. Grantee staff members plan to apply for a waiver amendment or a 1915(c) Independence plus waiver to sustain the initiative after the grant ends.
- **Vermont (RC)** has been using its Cash and Counseling pilot under an 1115 waiver program, and the Developmental Services Consumer-Directed Funding project to provide consumers greater flexibility and control of their services. Consumers have a cash allowance to hire their choice of workers and purchase other services and equipment that Medicaid does not cover**.**

Education Initiatives

- **Delaware (NFT-ILP)** developed a series of workshops to provide information to consumers on budgeting, banking, and decision-making to improve the money management skills needed to manage individual budgets.

- **Guam (CPASS)** has been working to educate persons with disabilities, family members, and professionals about the Individualized Budgeting concept.

3.3.2 Payment Rates and Methodologies

States are working to identify new methods for calculating provider payment rates to better address consumer needs. Most of these initiatives are in the early stages of development. Many span the full range of services offered for a given disability group, though some are service specific. They include non-capitated and capitated payment methodologies, flexible reimbursements, and payment methods for specific services. Examples include

Noncapitated Payment Methodologies

- **Massachusetts (NFT)** is working to establish a rate to allow intensified supports during transition from an LTC facility to the community, including periodic transitions by individuals with chronic illnesses who enter nursing homes for short stays and return to the community.
- **Montana (RC)** is developing a methodology and service rate to reimburse individualized services.
- **Oklahoma (CPASS)** is developing a flexible reimbursement infrastructure for consumer-directed services, to better relate compensation to the skills and demands the work requires, employment longevity, and the quality of service as evaluated by the consumer.
- **Washington (RC, NFT)** is developing, testing, and implementing a payment rate algorithm to be used with an HCBS assessment tool, which will provide up to 14 payment levels, depending on the assessment of individual needs.
- **West Virginia (CPASS)** staff members are working with the Bureau for Medical Services to establish an equitable payment methodology for consumers who choose consumer-direction to "cash out" funds that have been authorized for services within the Aged and Disabled Waiver. The methodology will likely be based on the monetary amounts associated with a participant's level of care as determined by eligibility assessments and re-assessments.

Capitated Payment Methodologies

- **Arkansas (RC)** is supporting development of a Program of All-inclusive Care for the Elderly (PACE) model, which uses a capitated Medicaid/Medicare rate for people age 55 and older who meet the criteria for nursing facility care.

- **Maryland (RC)** produced a report detailing a plan for implementing a wraparound capitated rate for services for children with serious emotional disabilities in Baltimore City and Montgomery County.
- **Oklahoma (RC)** is developing a capitated reimbursement methodology for comprehensive acute care and LTC services.
- **Vermont (RC)** is developing a Cash and Counseling pilot under its 1115 waiver that will provide individuals with a capitated cash allowance to hire their choice of workers and to purchase other services and goods.

Flexible Reimbursement

- **Indiana (CPASS)** is allowing consumers to negotiate a payment rate for their attendants, with a cap of $12/hour. As current attendant care wages range from $7 to $10 an hour, the negotiated rate may help consumers to attract and retain better workers.
- **Rhode Island (CPASS)** is developing a rate-setting methodology for the State's PASS program that will allow more flexibility by specifying a minimum and a maximum amount that families can pay for services.

Payment Methodologies for Specific Services

- **North Carolina (RC)** will allow consumers in consumer-directed pilots to use a portion of their budget to purchase items or services that increase their independence.

3.3.3 Money Follows the Person

States are developing and implementing a wide range of strategies to reform financing and service systems to allow funding to follow consumers to any setting. These initiatives are usually described as "money follows the person" (MFP) initiatives. Examples include

- **Massachusetts (RC)** is developing a pilot project to develop and evaluate a "money follows the person" option for individuals ineligible for the Medicaid consumer-directed program. Pilot participants will receive an individual budget based on their functional needs.
- **Maryland (NFT-ILP)** and **Nevada (CPASS)** helped to develop legislation establishing or studying a "money follows the person" program.
- **Wisconsin (NFT, NFT-ILP)** helped develop statutory and other provisions establishing a mechanism for money to follow the person from ICFs/MR to the community. Using these provisions, **Wisconsin (RC)** is exploring options for

ICF/MR funds to follow residents who transition to home and community services.

3.3.4 Consolidated Budgets

Although most states have separate budgets for institutional and community-based programs, some states are working to consolidate funding for all LTC services into one budget, so consumers can receive funding for needed services regardless of the setting. This approach differs from MFP, where a state maintains separate budgets for institutional and community services funding, but allows funding to move between budgets. Examples include

- **Indiana (NFT)** is working to create a seamless Medicaid LTC budget that funds consumers' choice of services. For example, if a nursing home resident wants services in their home, and a priority diversion/transition waiver slot is available, funding that would have paid for nursing home services would be used to pay for home services.
- **Oklahoma (RC)** is developing a model managed care service delivery system that combines delivery and reimbursement of acute and LTC services for persons in a single program.
- **Vermont (RC)** submitted an 1115 Waiver application to CMS to consolidate their budgets for nursing home and HCBS funding.

3.4 SERVICE CREATION/MODIFICATION

A major goal of the Systems Change grants program is to increase the availability of home and community services so that persons with disabilities of all ages who need a wide array of services can live and work in the community. Grantees in 41 states have a wide range of initiatives related to the development of home and community services. Although Grantee activities described in this section might also be appropriate to include in other focus areas, they are listed here because their primary intent is to create new CD programs or modify existing services. For discussion purposes, these initiatives are grouped into three categories:

- transition services,
- personal assistance services, and
- consumer-directed services.

As shown in Exhibit 7, 34 states are working on initiatives to create services or to modify personal assistance services to make them

Exhibit 7. 36 States with Service Creation/Modification Initiatives

State	Transition Services and Supports	Personal Assistance Services	Consumer-Directed Services
Alabama	•		
Alaska		•	
Arkansas	•		•
Colorado	•	•	
Connecticut	•		
Delaware	•		
District of Columbia		•	
Georgia		•	•
Guam			•
Hawaii			•
Idaho		•	
Indiana	•	•	•
Iowa			•
Kansas		•	
Louisiana		•	•
Maine			•
Maryland		•	
Massachusetts	•	•	
Michigan		•	
Minnesota		•	•
Mississippi		•	
Missouri			•
Nebraska			•
Nevada	•		
New Hampshire		•	•
North Carolina		•	
Northern Mariana Islands		•	
Ohio	•		
Oklahoma	•	•	
Oregon		•	•
Rhode Island		•	
South Carolina	•	•	•
Utah			•
Vermont		•	•
Washington		•	•
West Virginia	•	•	•
Total	**12**	**23**	**18**

more consumer-responsive. While only 11 states have initiatives to develop new consumer-directed services, Grantees in 41 states are involved in efforts to give consumer's more control over the services they receive (see Section 3.1).

3.4.1 Transition Services and Supports

In addition to strong case management services, persons transitioning from institutions need other services and assistance with a range of expenses, many of which are not traditionally covered under Medicaid or state-only LTC programs. Grantees in

12 states either found funding sources for these expenses or helped consumers find funding. Examples include

- **Arkansas (NFT)** and **Ohio (NFT)** have been working with staff from the waiver agencies to add transition and relocation services to existing waiver programs.
- **Colorado (NFT)** used grant funding to pay for transition expenses not covered under the waiver, such as rent and utility deposits.
- **South Carolina** (**NFT)** provided clients with immediate transition needs with special service packages and other items, including groceries, bathroom safety aids, a limited amount of furniture, nutritional supplements, and home modifications.
- **West Virginia (NFT)** used grant funds for transition and diversion services and supports not covered under Medicaid. The Grantee is working with the Real Choice and MIG Grantees and the state Olmstead committee to identify potential funding sources for these services and supports.

3.4.2 Personal Assistance Services

Using several approaches, Grantees in 23 states have been working on initiatives aimed at modifying personal assistance services to make them more consumer-responsive. Grantees described a range of approaches including

- amending rules to allow consumers to hire friends and family,
- amending rules to allow personal care services to be provided outside the home wherever consumers need them, and
- modifying service definitions to allow an expansion of the scope of services.

Examples of each of these approaches are listed below.

Friends and Family as Paid Caregivers

- **Alaska (RC)** plans to allow relatives of consumers, if qualified, to provide services in its pilot project.
- The **District of Columbia (CPASS, RC**) Grantee—the Medical Assistance Administration (MAA)—changed its regulations to permit family members other than legally responsible relatives (for example, spouses or parents of minor children) to be reimbursed for providing services.
- **Massachusetts (RC)** has implemented a pilot program that allows consumers to hire non-agency workers,

including friends and relatives. Consumers have individualized budgets and will design their spending plan with support from a community liaison.

Service Provision Outside the Home

- **Massachusetts (RC)** is developing a pilot project that will allow the provision of personal care outside the home and the payment of family and friends as caregivers.
- **Oklahoma (CPASS)** assisted in the drafting of legislation to assure that consumers can legally assume responsibility for directing their own care and are able to receive assistance in community settings outside the home.
- **Washington (RC)** and **Indiana (CPASS)** have made changes to allow attendant care services to be provided outside the home. In Indiana, consumer-directed care has been added as a service to the State's Aging & Disability waiver. Under this option, services may be provided wherever needed. In Washington, rules for all programs were amended to allow personal care assistance to be provided outside the home.

Modifying Service Definitions

- **Colorado (CPASS)** found that early inclusion of a representative of the Board of Nursing on its Advisory Committee helped to obtain buy-in and support for activities that relate to revision of Nurse Practice Acts. The Grantee also used an 1115 demonstration waiver to provide maximum flexibility in the way services are delivered.
- **Minnesota (CPASS)** added *Shared Care* to the Personal Care Attendant program, a service option that allows up to three consumers to share a direct service worker at the same time and in the same place.
- **Oklahoma CPASS** is working to expand the definition of consumer-directed personal assistance services under the 1115 waiver program to include health maintenance activities, companion services, assistance with consumer-direction management tasks, and other activities.

3.4.3 Creating Consumer-Directed Services

Grantees in 18 states have initiatives underway to develop consumer-directed programs or service options. Some are considering ways to increase the use of consumer direction in existing programs, including state plan and waiver programs. Examples include

- The **District of Columbia (CPASS, RC)** added consumer-directed attendant care to its waiver program.

- **Maine (RC)** is working to amend existing HCBS waiver programs to incorporate a consumer-directed option.
- **Nebraska (RC)** worked to revise regulations for the State's Personal Assistance Services program, to give consumers the option to hire, train, and direct workers to perform health maintenance tasks, which previously had been covered by the State's Nurse Practice Act.
- **New Hampshire (CPASS)** implemented a new consumer-directed personal care option under its waiver for elderly and chronically ill persons. Consumers using this option will be able to hire, schedule, train, and discharge their own workers. During the reporting period, 186 waiver participants used consumer-directed services.
- **Vermont (RC)** proposes to expand consumer-directed supports to participants in its 1115 waiver cash and counseling pilot, as well as the pilot project to provide direct funding to people with developmental disabilities. Consumers will have a flexible monthly allowance to hire workers and to purchase other services and goods.
- **West Virginia (CPASS, NFT)** Grantees worked together to modify the Medicaid state plan and some waiver programs to offer consumer-directed personal assistance services and supports. The State is considering adding a consumer direction option to the Mental Retardation/ Developmental Disabilities Waiver program.

3.5 LONG TERM CARE WORKFORCE

The high demand for services and relatively low supply of workers has created a shortage of direct service workers. This shortage can have a negative affect on the quality of LTC services through disruptions in the continuity of care, receipt of poorer quality or unsafe care, and reduced access to care.[3] Given the hard work these jobs require and the low pay and benefits that workers receive, it is difficult to attract workers, and new recruits may leave soon after being hired. As shown in Exhibit 8, Grantees in 39 states have workforce initiatives to improve the recruitment and retention of workers and the quality of direct care services. These initiatives are grouped into five categories:

- recruitment efforts,
- wage and benefit improvements,
- training and career ladders,
- changes in the work culture, and
- systems administration and planning.

Exhibit 8. 39 States with Workforce Initiatives

State	Recruitment	Wages & Benefits	Training & Career Ladders	Culture Change	Administration & Planning
Alaska	●		●	●	●
Arkansas	●	●	●		
California		●	●	●	
Connecticut	●		●		
Delaware	●	●	●		
District of Columbia		●	●		
Florida	●				
Georgia	●		●		●
Guam			●		
Idaho		●			
Illinois			●		
Indiana	●	●	●	●	●
Iowa	●				
Kansas	●	●	●		
Kentucky	●		●		●
Louisiana	●		●		
Maine				●	
Maryland	●		●		
Massachusetts	●				
Michigan		●	●		●
Minnesota	●	●			
Montana	●		●		
Nevada	●	●			
New Hampshire	●	●			
New Jersey	●	●	●		
North Carolina	●		●	●	●
Northern Mariana Islands			●		
Oklahoma		●			●
Oregon	●		●		
Pennsylvania			●		
Rhode Island	●		●		
South Carolina		●			
Texas	●	●			
Utah			●		
Vermont				●	
Virginia			●		
Washington	●	●			
West Virginia	●		●		
Wisconsin	●		●	●	
Total	**25**	**18**	**26**	**7**	**7**

The majority of the Grantees have initiatives focused on recruitment, training and career ladder development, and wages and benefits. Fewer Grantees have initiatives focusing on culture change and systems administration and planning. In the following subsections, we present examples of Grantee activities in each of the five categories to illustrate the type and range of initiatives they are undertaking.

3.5.1 Recruitment Initiatives

States, provider agencies, and other organizations need well-designed and cost-effective recruitment efforts to address the shortage of workers. Grantees have developed a diverse range of initiatives to recruit workers:

- Public awareness campaigns
- Job fairs
- Worker registries
- Backup systems

Examples of initiatives in each of these areas follow.

Public Awareness Campaigns

- **Arkansas (RC)** planned, implemented, and completed a public awareness campaign to help inform the public about the importance of direct service workers. **Arkansas (CPASS)** collaborated on the project, establishing a website (http://www.2beadsp.com) and a toll-free phone number for statewide recruitment.
- **North Carolina (RC),** as part of its public awareness activities, developed a website (http://www.dcwa-nc.org) for its newly formed Direct Care Workers' Association. The website provides descriptive information about the activities of the association, describes useful resources for direct service workers, and solicits members and corporate sponsors.

Job Fairs

- **Maryland (RC)** job fairs were successful in obtaining new workers for their HCBS waiver programs, enrolling 100 persons at the first fair. These regional job fairs targeted self-employed direct service workers who expressed an interest in providing personal assistance services through the waiver program. They provided needed training, certification, and background checks in a single venue. Of those job fair participants who were tracked, approximately 51 percent went on to become providers.

Worker Registries

- **Georgia (NFT)** developed and distributed six registries listing a total of 49 self-employed personal care assistants and 73 home care agencies. These registries are distributed quarterly to provider agencies and consumers. They were developed in relationship with Area Health Education Centers, will be expanded to include other areas of the State.

- **Minnesota (CPASS)** is developing a Personal Care Assistant (PCA) Online Worker Listing to provide consumers with quick and easy access to personal care assistants looking for work. PCAs will register online or via the Disability Linkage Line. The listing will provide a searchable database with contact information and work preferences of personal care assistants looking for work. Consumers will be able to screen potential workers by location, language fluency, and special skills (e.g., CPR).

Backup Systems

- **New Hampshire (CPASS)** developed a backup model using the federal work-study program. College students who are on call provide backup services in the event that regularly scheduled workers cannot work. The program uses Medicaid dollars to pay students when providing services to consumers and federal work-study dollars to pay students while they are on call.
- **Minnesota (CPASS)** contracted with four agencies to establish small networks of consumers (within Minnesota's consumer-directed program) who will have access to a registry of workers who work for other consumers and are on call for additional work. The Grantee educated Agency staff members about consumer direction and recruiting and training consumers.
- **Nevada (CPASS)** completed an activity to develop (1) reliable methodology to assure the availability of qualified backup, relief, and emergency PAS and (2) a procedure for obtaining these services, but concluded that a backup "system" is not practical. Instead, a backup must be preplanned for every consumer, must be directed by the consumer, and must include several options.

3.5.2 Wage and Benefit Initiatives

Direct service workers typically receive low wages and few benefits, making these jobs unattractive. Wage increases and other benefits can have a direct effect on both the recruitment and retention of workers. State budget crises have slowed development or impeded implementation of efforts to improve wages; nonetheless, several states reported successful wage initiatives. Similarly, some states have been working on initiatives to provide health insurance and other benefits, despite the current funding environment, and are working to identify other means of providing nonwage benefits. Examples include the following:

Wages

- The **District of Columbia (RC, CPASS)** worked to increase the reimbursement rate for workers by $2.00 per hour, and is reviewing the wages in contiguous states to develop a competitive wage scale that will attract individuals to the direct service workforce.
- **Illinois RC** worked to get new legislation passed that improves wages for personal assistants by increasing the wage annually through August 2007 to $9.35 per hour.
- **Nevada (CPASS)** worked to increase Personal Assistant pay in the State's Personal Assistance Services program by an average of 10 percent.

Health Insurance and Other Benefits

- **California (RC)** is working to identify nonwage benefits that contribute to a positive consumer-provider relationship in the State's In-Home Supportive Services program.
- **New Hampshire (CPASS)** developed a Health Reimbursement Arrangement through which direct service workers can receive primary and preventive care. This Grantee is also working to provide workers with access to a credit union and a low-interest loan program.

3.5.3 Training and Career Ladder Initiatives

Workers often cite the lack of adequate training for direct service jobs. Improved training may be important to help workers develop competencies and functional skills that will improve their confidence and job satisfaction, and ultimately lead to worker retention. Career ladder development for workers is also needed to reduce the turnover rate and develop a cadre of qualified workers. States are developing pre-service and in-service training initiatives as well as career ladders with training components. However, Grantees have had difficulty identifying funding for wage increases for workers wanting to move up a career ladder. Examples include

- **Georgia (RC)** implemented medication administration policies and regulations to allow certified direct service workers to distribute medications, a process intended to be a cost effective method for supporting individuals with mental illness and/or developmental disabilities in the community.
- **Kentucky (RC)** developed a draft pre-service curriculum for Direct Support Workers that allows them to gain an academic certificate upon completion. The curriculum will

be taught using a web-based strategy managed by the State's community college system.

- **Louisiana (NFT)** helped pass new legislation mandating standards for participation and training for Medicaid HCBS providers.
- **Louisiana (RC)** developed a pre-service curriculum for Direct Support Professionals and an associated career ladder proposal, and conducted 17 training sessions.
- **Montana (CPASS)** is developing regional training centers that will offer standardized home health aide, certified nurse assistant, and personal assistant training. The Grantee also developed a code of ethics for caregivers and identified training needs for caregivers.
- **North Carolina (RC)** is planning its first Direct Care Worker Institute sponsored by the State's new direct service worker association to provide educational training. The target audience includes direct service workers, providers, consumers, family members, and other interested individuals. The Grantee has also arranged for staff from the Paraprofessional Healthcare Institute to provide train-the-trainer sessions on coaching and supervision skills for 44 workers.
- **Virginia (RC)** provided Enhanced Care Assistant Training to 103 personal care aides and is creating a video to train other personal care aides.

3.5.4 Culture Change Initiatives

Initiatives to improve the work culture and to recognize or empower workers in their jobs may be as important to retaining workers as efforts to improve wages and benefits. Successful culture change efforts should improve both the recruitment and retention of workers by making the environments in which they work less stressful and more supportive over time. To improve the work culture, Grantees have undertaken initiatives to create worker associations, support groups, and recognition programs. Both the states and direct service workers view worker associations as potentially important vehicles for helping workers take ownership of their work and for raising worker visibility among the public generally and policy makers specifically. Although support groups are less formal than worker associations, they provide opportunities for workers to support and learn from each other. Recognition programs make workers feel appreciated, an important factor in retention. Examples include

- **Maine (RC)** has developed the Personal Assistance Workers' Association, which is gaining recognition across the State. Its representatives have been invited to represent the interests of direct service workers on boards and in meetings.
- **North Carolina (RC)** has developed the Direct Care Workers Association of North Carolina. The association has a mission statement, bylaws, a functioning board, and has filed a 501(c)3 application as a nonprofit organization. The Grantee has also developed a membership brochure and database and is conducting a membership drive that has recruited 28 members and collected $3,400 in fees/sponsorships.
- **Vermont (RC)** is also developing a paraprofessional organization with nine direct service workers serving on a steering committee. To help develop the association, the Grantee commissioned a concept paper that reviewed paraprofessional associations nationally and made suggestions for forming an association in Vermont. In addition, the Grantee worked with the direct service workers involved to establish a name, mission statement, guiding values, and membership policy.

3.5.5 Administrative Planning Initiatives

Grantees in seven states have initiatives to develop new models of service delivery, collect data for planning, and define direct service jobs and worker qualifications. Grantee activities include developing plans for public authorities, collecting various types of data to track recruitment trends, and identifying new types of jobs to meet changing workforce needs. Examples include

- **Alaska (CPASS)** helped develop new regulations permitting flexibility in qualifications for becoming a Personal Assistant. The regulations have moved through the public comment process, are being reviewed by the Attorney General's office, and the Grantee expects they will be implemented in FY 2005.
- **Kentucky (RC)** is developing job profiles denoting the knowledge and skills needed for several job positions, including (1) direct service workers for community residential settings, (2) direct service workers who provide support in day treatment and other day program settings, (3) mid-level supervisors with direct supervisory responsibility over direct care workers, and (4) case managers.
- **Michigan (CPASS)** petitioned the Governor to authorize development of a public authority model for employing

direct care workers after conducting a needs assessment on the State's workforce issues. The Grantee developed a plan for a public authority model that will provide training that can lead to the development of career ladders and help workers obtain benefits such as a low-income health care plan, subsidized housing, and tax credits. The public authority's registry will help workers find additional consumers in need of backup assistance when they want to increase their hours worked.

- **North Carolina (RC)** added two additional items in the past year to the State's data collection effort to analyze annual worker turnover. The State collects data on workers through the license renewal application process for adult care homes, home care, and nursing facilities.

3.6 QUALITY ASSURANCE

A major challenge for federal and state policymakers is to design, implement, and maintain effective quality assurance and quality improvement systems that are well-suited to community living. Grantees in 24 states have implemented initiatives to improve the quality of services, as shown in Exhibit 9. The quality initiatives are grouped into three broad categories:

- addition of a consumer focus to the quality monitoring system,
- development of data systems for quality monitoring, and
- development and implementation of specific components of quality management systems, including consumer-focused quality assurance tools, processes, or consumer satisfaction surveys.

Grantees primarily reported adding a consumer focus to quality management systems and developing and implementing consumer-focused components of quality management systems. Fewer Grantees reported developing data systems for quality monitoring. In the following subsections, we present examples of Grantee activities in each of the three categories to illustrate the type and range of initiatives they are undertaking.

Exhibit 9. 24 States with Initiatives to Improve Quality Management System

State	Consumer Focus	Data System Development	Specific Consumer-Focused Components
Arkansas	•		•
Colorado	•		
District of Columbia		•	
Guam			•
Hawaii			•
Indiana			•
Kansas	•		
Kentucky	•		
Louisiana			•
Maine	•		
Maryland	•		•
Massachusetts	•	•	•
Michigan	•	•	•
Minnesota	•	•	
Mississippi			•
Nevada	•		•
North Carolina			•
Ohio			•
Oklahoma	•	•	
Vermont	•		
Virginia	•		
Washington		•	•
West Virginia	•		
Wyoming			•
TOTAL	**14**	**6**	**14**

3.6.1 Add a Consumer Focus to Quality Monitoring Systems

A frequently expressed concern about quality assurance (QA) systems is their lack of quality indicators important to consumers. To address this concern, Grantees described initiatives underway to add a consumer focus to quality monitoring systems. Initiatives include the development of consumer-focused quality indicators, and the implementation of consumer-focused quality initiatives in pilot programs and in new and existing programs. Examples include

Consumer-Focused Quality Indicators

- **Maine (RC)** has developed a consumer-driven approach to quality management that enables those receiving home and community services to define quality. To assure that the quality indicators were consumer-focused, the Grantee involved consumers, experts, and policymakers in their development. The State has created a web-based database of quality measures for home and community services organized according to the HCBS Quality Framework (http://qualitychoices.muskie.usm.maine.edu/qualityindicators/index.htm).

- **Michigan (RC)** involved consumers in the development of quality indicators to be used across multiple LTC settings. The development of quality indicators was a component of a larger goal to re-engineer the State's performance improvement system to be more consumer-directed and outcome oriented. State and local providers will use these indicators as the basis for quality improvement activities, such as tracking progress and identifying targets for performance improvement.

Consumer-Focused Quality Initiatives in Pilot Programs

- **Arkansas (NFT)** developed an ombudsman program for HCBS waivers (named *Your Voice, Your Choice)* to address consumers' issues and complaints. Concerns and complaints made to the ombudsman will be documented and used to identify areas for quality improvement.
- **Kansas (CPASS)** developed consumer-focused quality assurance standards for consumer-directed services through the work of the grant's advisory council (comprising consumers, parents, advocates, service providers, state officials, and other stakeholders). The Grantee has also been working with the State to modify its quality monitoring and improvement data system for LTC services and supports, to include quality indicators relevant to consumer-directed services.
- **Kentucky (RC)** is working to improve the quality and outcomes of services for persons receiving home and community services by increasing citizen involvement in quality monitoring for people with mental retardation and other developmental disabilities. As part of this initiative, the ARC of Kentucky has been developing methodology and protocols for quality monitoring of HCBS waiver providers.
- **Maryland (RC)** developed service-specific performance measures for community LTC programs. Starting January, 2004, the Grantee will be administering the Participant Experience Survey—an instrument designed by MEDSTAT for CMS—to approximately 500 waiver participants to assess their satisfaction with services. The information will be used to inform future quality improvement efforts.
- **Nevada (CPASS)** designed a universal client satisfaction tool to evaluate all personal assistance providers in the State and to enable a comparison of consumer satisfaction across all programs. The State has also adopted a policy requiring that the tool be used in face-to-face interviews with at least 25 percent of all program clients in a given year, so that no client will go more than 4 years without an in-person interview.

- **Virginia (RC)** is addressing gaps in quality assurance and lack of satisfaction with HCBS waiver programs through the development of performance, outcome, and satisfaction measures. The State is also pilot testing a quality assurance program for the State's Elderly and Disabled waiver, which includes a client satisfaction survey.
- **West Virginia (CPASS)** is developing a system to compare Medicaid and non-Medicaid personal assistance service providers with respect to consumer involvement, consumer satisfaction, service provision, attendant recruitment, backup response, and other features important to consumers. A statewide multimedia campaign and a website will be used to provide the comparative information to consumers.

3.6.2 Develop a Data System for Quality Monitoring and Improvement

To be effective, quality assurance systems must have a data system for gaining current information about how program participants are faring. They must also be designed to evaluate that information in a timely manner to remedy problems expeditiously and effectively. Examples of Grantees developing such systems include

- The **District of Columbia (RC)** is developing a database to track the quality of services.
- **Massachusetts (RC)** and **Michigan (RC)** are developing data collection mechanisms that will be used to continuously improve the quality assurance systems they are designing for pilot projects. The data collected for Michigan's pilot project on individual budgeting will include information on quality of life, level of independence, and satisfaction. This information will be used not only to improve the pilot program, but to inform a planned Independence Plus waiver.
- **Minnesota (RC)** is developing an automated consumer feedback system to evaluate and measure consumer satisfaction with the service delivery system and consumer quality of life outcomes. The website and database that the State was developing for the *Disability Linkage Line*—a service and resource information source for consumers with disabilities and chronic illnesses—will incorporate a system for consumers to provide feedback regarding service providers.
- **Oklahoma (RC)** developed a contracting infrastructure that requires all Medicaid Personal Assistance Services and 1915(c) ADvantage waiver provider agencies to have an

approved continuous quality improvement plan. The State is developing a Quality Waiver Evaluation System Tracking (QWEST) software system, which will include a statewide consumer complaint/concern discovery and remediation system for ADvantage waiver participants.

- **Washington (RC)** developed a new quality assurance system that will allow the State to retrieve data on deficiencies, and a monitoring system for incident and mortality reports, to identify trends and patterns. The information will be used to improve policy, staff training, and consumer services.

3.6.3 Develop and Implement Specific Consumer-Focused Components

In addition to broad initiatives focused on quality assurance systems and database development, many Grantees have undertaken more narrowly focused quality assurance initiatives. These include Grantees who are developing and implementing specific components of quality management systems (such as mechanisms for consumers to provide feedback on the quality of their services) and assessing consumer satisfaction with current and pilot programs. Examples include

Development of Mechanisms for Consumer Feedback

- **Hawaii (RC)** is developing a quality assurance process for the newly created web-based, cross-agency, cross-disability, single entry point (SEP) for LTC services and supports. The process will allow consumers to rate their providers online, and the website will post a summary of the results.
- **Minnesota (RC)** is developing an information and referral service that will include a mechanism for consumers to provide feedback on service quality.
- **Ohio (RC)** developed a web-based, comprehensive information system that provides information on all benefits and services available for adults and children with disabilities. Consumers using the *No Wrong Door Ohio* website will be able to provide feedback about the services received; if applicable, providers will be informed of their service deficiencies.

Assessment of Consumer Satisfaction with Current Programs

- **Alaska (RC)** is responding to a request by the Division of Senior and Disabilities Services (DSDS) to modify its consumer survey into a feedback form that could be downloaded from the State's personal care attendant (PCA)

website or obtained at PCA agencies. The wide distribution of this feedback form will allow consumers to have a direct and anonymous method for providing feedback, complaints, or suggestions to DSDS regarding the agency-based or consumer-directed PCA programs.

- **Indiana (NFT)** collaborated with the Bureau of Quality Improvement Services, which has been conducting post-transition follow-up visits to individuals who are diverted or transitioned under the grant to assess their satisfaction with services. The State has used the data to improve the diversion/transition process.
- **Louisiana (NFT)** is developing a quality assurance process and Citizens Monitoring process to assess individuals who have transitioned.
- **Michigan (NFT)** is using a computer system based on the MDS Home Care methodology to monitor quality and outcomes for persons transitioned under the grant.
- **Washington (RC)** developed a consumer survey that will be included in a Quality Assurance home visiting process that the Grantee developed. This "follow-along" monitoring system, which is focused on the consumers' quality of life, is for people with developmental disabilities who move from institutions to the community.
- **Wyoming (NFT)** is conducting a consumer satisfaction survey that the University of Wyoming will analyze.

Assessment of Consumer Satisfaction with Pilot Programs

Grantees in a few states were conducting consumer surveys to obtain feedback on pilot programs. Examples include

- **Guam (CPASS)** surveyed consumers and families to determine their satisfaction with an Individualized Budgeting pilot program.
- **Mississippi (RC)** is assessing satisfaction with supports for persons with serious mental illness, which are based on a person-centered planning model.
- **North Carolina (RC)** is assessing consumer and worker satisfaction for participants in its consumer-directed pilot programs.

3.7 GRANTEES' CHALLENGES

3.7.1 Types of Challenges

During the current reporting period, Grantees in many states described challenges related to their LTC systems change activities as well as administrative challenges. Generally, the challenges are unique to their individual efforts to improve the LTC systems in their respective states. The primary administrative challenges Grantees described were finding staff for grant activities, state budget deficits, and delays in subcontracting.

Challenges to Systems Change

Grantees reported challenges unique to grant implementation. In addition, several Grantees identified a lack of affordable, accessible housing as a major challenge. Examples of challenges include

- **Delaware (RC)** reported that political challenges to their initial attempts to secure funding for an alternative financing program through the state legislature slowed establishment of the low-interest assistive technology loan program.
- **Georgia (RC)** identified lack of appropriate housing as the reason for delay in implementing the supported housing demonstration project. The Grantee is partnering with the Center for Mental Health Services Olmstead Housing Coalition in a housing demonstration project that will transition 50 individuals with severe mental illness from mental heath institutions. In the reporting period, no housing was available for this project. The Grantee has trained staff and developed the evaluation component for the project to implement once housing becomes available.
- **Kentucky (RC)** reported that an expected partnership with the Kentucky Assistive Technology Loan Corporation to establish a loan program for home modifications was unsuccessful due to the inability of consumers to assume loan commitments.
- **Maryland (NFT)** noted the lack of affordable and accessible housing for individuals exiting nursing facilities as a major challenge, particularly due to the difficulty Public Housing Authorities (PHA) have had in obtaining more housing vouchers. Some individuals who desired to leave a nursing facility had limited income, making it difficult to afford high rents. When they were unable to locate appropriate housing within their income range, the vouchers had been returned unused to the local PHA.

- **Minnesota (CPASS)** noted that older adults in managed care were not able to use the Personal Care Attendant (PCA) Choice option because managed care providers were not required to contract with PCA Choice providers. The Grantee also noted the reluctance of health care and social service professionals to accept consumer-directed PCA services and consumer reluctance to accept staffing responsibility for PCA supervision, training, and backup plans.

Administrative Challenges

In addition to reporting on challenges that affected the Grantees' ability to implement activities related to systems change, some Grantees continued to face administrative challenges. Exhibit 10 lists the types of administrative challenges Grantees faced and the percent of Grantees reporting each type of challenge.

Exhibit 10. Administrative Challenges Experienced by States

Type	Percent of Grantees Experiencing the Challenge
Staffing Problems	68
State Budget Crisis	65
Subcontracting Delays	54
Budget Reduction*	25
State Travel Restrictions	12

*Budget reductions negotiated with CMS apply only to the FY 2002 Grantees.

The state budget crises continued to be a problem for many Grantees. For example, the budget crisis in a number of states contributed to staffing problems, including office and department reorganizations, changes in political leadership, grant staffing changes, and early retirement options taken by staff.

Several states also reported that cuts in state budgets affected grant activities by slowing grants management and hiring and contracting processes, and reducing services. States reported delays due to administrative procedures, unforeseen termination of contracts, lack of response to requests for proposals (RFPs) to implement key components of grant activities, and lack of expertise among some subcontractors.

3.8 CONSUMER INVOLVEMENT IN SYSTEMS CHANGE ACTIVITIES

During the reporting period, Grantees in almost all states indicated that consumers and consumer partners participated in systems change activities. Grantees involved consumers in grant planning and implementation through formative and summative evaluation activities. Consumers serve as members of consumer task forces and advisory committees and in this capacity provide oversight for all grant activities. Consumers are also assisting in grant implementation, by providing input on specific grant activities in focus groups, meetings, and other venues. Finally, Grantees are soliciting the input of consumers to assess the grant's impact through consumer satisfaction surveys and focus groups.

3.8.1 Consumer Involvement in Formative Evaluation Activities

A primary method for incorporating formative learning into the grant implementation process has been the use of advisory committee or consumer task force meetings. These meetings are used to track, assess, and coordinate grant activities, and to identify barriers and methods to address them. In addition to serving on committees or task forces, consumers participated in planning meetings, served on grant subcommittees, and developed, tested, and evaluated outreach materials. They also reviewed and tested grant products, including websites and provider training materials, and assisted in the development of grant evaluation plans. Many Grantees have also conducted interviews, surveys, and focus groups with consumers and consumer partners (e.g., consumer task force members), grant staff, state officials, and other stakeholders (e.g., local commission or board chairpersons) to obtain their views about grant progress and goal achievement.

Of the more than 2,000 members serving on advisory committees and task forces, nearly half are individuals with disabilities, and approximately one-quarter are consumer advocates. Grantees engaged many of these individuals in focus groups and surveys to inform grant planning and implementation. Exhibit 11 summarizes the types of formative learning activities in which consumer partners were involved.

Exhibit 11. Activities of Consumer Partners on Consumer Advisory Committees or Task Forces

Types of Consumer Involvement	Number of States
Participated on committees	48
Reviewed grant products	48
Reviewed outreach materials	40
Developed outreach materials	28
Developed evaluation plans	22
Pilot tested outreach materials	25
Pilot tested grant products	28
Participated in planning meetings	45

Participation on Advisory Committees or Consumer Task Forces and Engagement in Outreach Activities

- **Connecticut (RC), and Kansas (CPASS)** used grant staff meetings and advisory committee and stakeholder group meetings to review quarterly progress on grant goals and objectives.
- **Oregon's (RC)** consumer task force, with the assistance of the Oregon Health & Science University Center on Self-Determination, formulated a comprehensive evaluation plan to determine if the grant achieved its goals.
- **Texas (NFT-ILP)** project staff provided quarterly reports to the Austin Resource Center for Independent Living Board of Directors, which conducted quarterly reviews of all program and financial activities to ensure achievement of the grant's goals and activities. Feedback from the consumer task force and the State's management team were also included in project reports, and project staff received feedback from the designated Health and Human Services Commission and Texas Department of Human Services liaisons.
- **Alabama (RC)** formed a Grassroot Advocacy Group to serve as a vehicle for consumer input to grant activities for individuals with mental retardation and/or developmental disabilities.
- **Delaware (NFT)** engaged a group of consumers, consumer advocates, state agency staff, and others to assist with the development of outreach and training materials on community options.

- **Kansas (RC)** trained 45 consumers to accompany screeners in nursing facilities to provide peer support and information about community options to residents.

Stakeholder and Consumer Interviews, Surveys, and Focus Groups

- **Alaska (RC, CPASS, NFT)** conducted regular interviews with a wide array of stakeholders, including consumer partners, to ensure that grant implementation was proceeding in an efficient and timely manner.
- **Massachusetts (RC)** surveyed stakeholders, including members of a collaborative team and a consumer planning and implementation group, to identify the strengths and weaknesses of the grant and its implementation.
- **Montana (CPASS)** held 21 focus groups with consumers and other stakeholders around the State to discuss the development of a code of ethics for caregivers and caregiver training needs. Over 300 people attended and provided valuable feedback on changes that need to be made in the Personal Assistance Program.

3.8.2 Consumer Involvement in Summative Evaluation Activities

Many Grantees reported developing and conducting consumer surveys, interviews, and focus groups as one way to assess outcomes and the impact of grant activities.

Consumer Interviews, Surveys, and Focus Groups

- **Alabama (NFT)** has been collecting information on consumer quality of life and family satisfaction with health care services associated with patient care for its hospital-to-home transition program. The State has also been working on plans to assess family caregiver satisfaction for its nursing home-to-home transition program, once it is implemented.
- **Delaware (NFT)** has contracted with Rutgers Center for State Health Policy (CSHP) to conduct a program evaluation that will survey and interview consumers involved in transitions and their families. Rutgers will also interview nursing home residents who elected not to transition.
- **Delaware (RC)** has developed plans to interview consumers to determine whether they perceive an increase in the availability of assistive technology services and equipment.
- **Hawaii (CPASS)**, with input from consumer self-advocates, used the Department of Health's Core Indicator Survey to design a consumer survey. The survey will be

administered in project sites participating in the demonstrations that support individualized planning and the management of personal assistance services.

- **Indiana (NFT, RC)** are using a customer satisfaction survey used by the Bureau of Quality Improvement Services to allow state staff to independently assess the success of grant efforts. The survey will ascertain whether individuals felt that the level and quality of services and supports they received in the community were adequate and how the community supports compared to those received in the nursing facility.
- **Mississippi (RC)** contracted with the University of Mississippi to administer several assessments to each of the consumers who participated in the person-centered planning program in three community mental health regions. The purpose of the assessments is to determine the program's impact on individuals' sense of empowerment, the ability to make decisions, satisfaction with services, quality of life, and other quality indicators. The State is also conducting an annual survey of individuals with mental illness to discuss their experience with the program.
- **North Carolina (CPASS)** is planning to conduct focus groups with participants in the consumer-directed pilot programs to determine how much control individuals feel they have over their services and supports.
- **Wisconsin (NFT-ILP)** and **Wyoming (NFT)** are planning to conduct follow-up interviews with consumers at least three months post-transition to evaluate community stability.

4 Looking Forward

The Systems Change grants are providing seed money for a multi-year effort to build the state infrastructure needed to provide consumer-responsive LTC systems. CMS allowed Grantees exceptional flexibility in selecting the initiatives they believe will yield the most significant improvement in a state's home and community service system.

As the findings illustrate, at the end of Year Two of the grant program, states are engaged in a wide range of LTC Systems Change activities, and are involving consumers and other stakeholders in their efforts. In many states, Grantees are combining resources across multiple Systems Change grants—as well as Medicaid Infrastructure grants and other sources of funding—to leverage resources and coordinate systems change efforts.

Though the FY 2001 Grantees are at the end of the 3-year grant period—September 2004—virtually all have received no-cost extensions to continue grant activities for a fourth year. Most will be completing activities that had a late start, evaluating their grant activities, and working to ensure that Systems Change initiatives are sustained after the grant ends.

The FY 2002 Grantees will continue to focus on grant implementation and evaluation in their third year. Due to delays in grant initiation, we expect that a large number of these Grantees will also apply for no-cost extensions to enable the completion of grant activities.

The Third Annual Report will contain information on the Year Two activities of the FY 2002 Grantees and the Year One activities of the FY 2003 Grantees.

RTI will produce a final report for each FY Grantee group, based on information they provide in their final reports and evaluations. RTI's final reports will present information about each state's accomplishments across all of the grants awarded in the same fiscal year.

5 Endnotes

[1]Burwell, B., S. Eiken, and K. Sredl. (2002, May). "Medicaid Long-Term Care Expenditures in Fiscal Year 2001" (Internal memorandum). Medstat Group. Cambridge, MA.

[2]Burwell, B., S. Eiken, and K. Sredl. (2004, May). "Medicaid Long-Term Care Expenditures in Fiscal Year 2003" (Internal memorandum). Medstat Group. Cambridge, MA.

[3]Anderson, W.L., Wiener, J.M., Greene, A.M., and J. O'Keeffe. (2004, April). *Direct Service Workforce Activities of the Systems Change Grantees, Final Report*. Baltimore, MD: U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services.

Appendix A

State Awards by Grant Type and Total Award Amount, FY 2001–2002

APPENDIX A
STATE AWARDS BY GRANT TYPE AND TOTAL AWARD AMOUNT, FY 2001–2002

State	Community PASS		NFT – State		NFT – ILP		Real Choice		Total $ Amount Awarded
	2001	2002	2001	2002	2001	2002	2001	2002	
Alabama				•	•		•		$3,220,000
Alaska	•		•					•	$3,085,000
Arkansas	•			•			•		$2,883,444
California						•		•	$1,722,500
Colorado		•	•					•	$2,645,147
Connecticut			•					•	$2,185,000
Delaware				•		•	•		$2,036,772
District of Columbia		•						•	$2,110,000
Florida							•		$2,000,000
Georgia			•		•			•	$2,412,211
Guam	•						•		$973,106
Hawaii		•					•		$2,075,000
Idaho							•		$1,102,148
Illinois							•		$800,000
Indiana		•	•					•	$2,880,000
Iowa							•		$1,385,000
Kansas		•						•	$2,110,000
Kentucky							•		$2,000,000
Louisiana				•				•	$1,985,000
Maine							•		$2,300,000
Maryland			•		•		•		$2,635,000
Massachusetts			•				•		$2,155,000
Michigan	•		•				•		$3,525,972
Minnesota	•					•	•		$3,600,000
Mississippi								•	$1,385,000
Missouri							•		$2,000,000
Montana	•							•	$2,235,000
Nebraska				•			•		$2,600,000
Nevada	•							•	$2,040,988
New Hampshire	•		•				•		$3,970,000
New Jersey				•		•	•		$3,000,000

(continued)

State	Community PASS		NFT – State		NFT – ILP		Real Choice		Total $ Amount Awarded
	2001	2002	2001	2002	2001	2002	2001	2002	
New Mexico								•	$1,385,000
New York								•	$1,385,000
North Carolina		•		•			•		$2,925,000
North Dakota								•	$900,000
Northern Mariana Islands								•	$1,385,000
Ohio				•				•	$1,985,000
Oklahoma	•							•	$2,235,000
Oregon							•		$2,000,996
Pennsylvania								•	$1,385,000
Rhode Island	•			•				•	$2,524,730
South Carolina				•			•		$2,900,000
Tennessee		•					•		$2,493,604
Texas					•			•	$1,693,178
Utah						•		•	$1,785,000
Vermont							•		$2,000,000
Virginia							•		$1,385,000
Washington			•					•	$2,155,000
West Virginia		•	•					•	$2,590,674
Wisconsin			•		•			•	$2,635,000
Wyoming				•					$600,000
Total	**10**	**8**	**11**	**11**	**6**	**5**	**25**	**25**	**$109,405,470**

Appendix B

Lead Agencies Receiving Grants, by State

APPENDIX B
LEAD AGENCIES RECEIVING GRANTS, BY STATE

State	Grant Type	Grantee Organization
Alabama	NFT-ILP	Mid-Alabama Chapter of the Alabama Coalition of Citizens with Disabilities, DBA Birmingham Independent Living Center
Alabama	NFT-SP	Alabama Department of Senior Services, State Unit on Aging
Alabama	RC	Alabama Medicaid Agency, Long-Term Care Division
Alaska	CPASS	Department of Administration, Division of Senior Services
Alaska	NFT-SP	Department of Administration, Division of Senior Services
Alaska	RC	Department of Health and Social Services, Division of Mental Health and Developmental Disabilities
Arkansas	CPASS	Department of Human Services, Division of Developmental Disabilities (DDS)
Arkansas	NFT-SP	Department of Human Services Division of Aging and Adult Services
Arkansas	RC	Department of Human Services, Division of Aging and Adult Services
California	NFT-ILP	Community Resources for Independence
California	RC	California Department of Social Services
Colorado	CPASS	Department of Health Care Policy and Financing
Colorado	NFT-SP	Department of Health Care Policy and Financing, Office of Medical Assistance
Colorado	RC	Department of Health Care Policy and Financing
Connecticut	NFT-SP	Department of Social Services, Health Care Financing
Connecticut	RC	Connecticut Department of Social Services
Delaware	NFT-ILP	Independent Resources, Inc.
Delaware	NFT-SP	Delaware Health and Social Services, Division of Services for Aging and Adults with Physical Disabilities
Delaware	RC	Delaware Health and Social Services
District of Columbia	CPASS	Department of Health, Medical Assistance Administration
District of Columbia	RC	Department of Health, Medical Assistance Administration
Florida	RC	Florida Department of Management Services, Americans with Disabilities Act Working Group
Georgia	NFT-ILP	disABILITY LINK
Georgia	NFT-SP	Georgia Department of Community Health, Division of Medical Assistance, Aging & Community Services
Georgia	RC	Georgia Department of Human Resources
Guam	CPASS	Department of Integrated Services for Individuals with Disabilities
Guam	RC	Department of Public Health and Social Services, Division of Public Health
Hawaii	CPASS	State of Hawaii, Department of Health
Hawaii	RC	Department of Human Services
Idaho	RC	Department of Health and Welfare, Division of Family and Community Services Idaho State University Institute of Rural Health
Illinois	RC	Illinois Department of Human Services

(continued)

State	Grant Type	Grantee Organization
Indiana	CPASS	Family and Social Services Administration
Indiana	NFT-SP	Family and Social Services Administration
Indiana	RC	Family and Social Services Administration
Iowa	RC	Iowa Department of Human Services, Division of MH/DD
Kansas	CPASS	The University of Kansas Center for Research, Inc.
Kansas	RC	Department of Social and Rehabilitation Services, Resource Development
Kentucky	RC	Kentucky Cabinet for Health Services
Louisiana	NFT-SP	Louisiana Department of Health and Hospitals
Louisiana	RC	State of Louisiana Department of Health and Hospitals
Maine	RC	Maine Department of Human Services, Bureau of Medical Services
Maryland	NFT-SP	Department of Human Resources (DHR), Office of Personal Assistance Services
Maryland	NFT-ILP	Making Choices for Independent Living, Inc.
Maryland	RC	Department of Mental Health and Hygiene
Massachusetts	NFT-SP	Department of Mental Retardation, Division of Systems Integration
Massachusetts	RC	Center for Health Policy and Research, University of Massachusetts Medical School
Michigan	CPASS	Department of Community Health, Long-Term Care Initiative
Michigan	NFT-SP	Department of Community Health, Long-Term Care Initiative
Michigan	RC	Department of Community Health, Long-Term Care Programs
Minnesota	CPASS	Department of Human Services, Continuing Care for Persons with Disabilities
Minnesota	NFT-SP	Metropolitan Center for Independent Living
Minnesota	RC	Department of Human Services, Continuing Care for Persons with Disabilities
Mississippi	RC	Department of Mental Health
Missouri	RC	Department of Social Services
Montana	CPASS	Department of Public and Human Services, Senior & Long-Term Care Division
Montana	RC	Department of Public Health and Human Services
Nebraska	NFT-SP	Department of Health and Human Services, Finance and Support
Nebraska	RC	Nebraska Department of Health and Human Services, Finance and Support
Nevada	CPASS	Department of Employment, Training & Rehabilitation, Office of Community Based Services
Nevada	RC	Nevada Department of Human Resources
New Hampshire	CPASS	Granite State Independent Living
New Hampshire	NFT-SP	DHHS, Elders Division
New Hampshire	RC	Department of Health and Human Services
New Jersey	NFT-ILP	Resources for Independent Living, Inc. (RIL)
New Jersey	NFT-SP	Department of Health and Senior Services
New Jersey	RC	New Jersey Department of Human Services
New Mexico	RC	Human Services Department, Medical Assistance Division
New York	RC	New York Department of Health

(continued)

State	Grant Type	Grantee Organization
North Carolina	CPASS	Department of Health and Human Services
North Carolina	NFT-SP	North Carolina Department of Health and Human Services
North Carolina	RC	NC Department of Health and Human Services
North Dakota	RC	State of North Dakota
Northern Mariana Islands	RC	Governor's Council on Developmental Disabilities
Ohio	NFT-SP	Ohio Department of Job and Family Services
Ohio	RC	Ohio Department of Job and Family Services
Oklahoma	CPASS	Oklahoma Department of Human Services, Aging Services Division
Oklahoma	RC	Oklahoma Department of Human Services, Aging Services Division
Oregon	RC	Oregon Department of Human Services
Pennsylvania	RC	Department of Public Welfare
Rhode Island	CPASS	Department of Human Services
Rhode Island	NFT-SP	Department of Human Services, Center for Adult Health
Rhode Island	RC	Department of Human Services, Center for Adult Health
South Carolina	NFT-SP	Department of Health and Human Services, Office of Senior and Long-Term Care
South Carolina	RC	Department of Health and Human Services
Tennessee	CPASS	Department of Finance and Administration
Tennessee	RC	Department of Mental Health & Developmental Disabilities
Texas	NFT-ILP	Austin Resource Center for Independent Living (ARCIL)
Texas	RC	Texas Health and Human Services Commission
Utah	NFT-ILP	Utah Independent Living Center
Utah	RC	Department of Human Services
Vermont	RC	Agency for Human Services
Virginia	RC	Department of Medical Assistance Services, Long-Term Care & Quality Assurance
Washington	NFT-SP	Department of Social and Health Services
Washington	RC	Department of Social and Health Services
West Virginia	CPASS	West Virginia University Research Corporation
West Virginia	NFT-SP	Department of Health and Human Resources
West Virginia	RC	Department of Health and Human Resources
Wisconsin	NFT-ILP	Great Rivers Independent Living Center
Wisconsin	NFT-SP	Department of Health and Family Services, Division of Supportive Living
Wisconsin	RC	Department of Health Family Services, Division of Supportive Living
Wyoming	NFT-SP	Wyoming Department of Health, Aging Division

Appendix C

FY 2003 Grantees

APPENDIX C
FY 2003 GRANTEES

As reported in Section 1.2, CMS awarded more than $33 million in Systems Change Grants for Community Living in FY 2003. The awards build on the roughly $125 million in grants awarded in the previous 2 years to help states improve their community-based services. CMS awarded a total of 75 grants across three broad categories—Research and Demonstration, Feasibility, and Technical Assistance—a total of 10 grant types.[1]

Exhibit C-1. Quality Assurance and Improvement in Home and Community-Based Services

Purpose: Assist states to (1) fulfill their commitment to assuring the health and welfare of individuals who participate in the state's home and community-based waivers under §1915(c) of the Social Security Act, (2) develop effective and systematic methods to meet statutory and CMS requirements by the use of ongoing quality improvement strategies, and (3) develop improved methods that enlist the individual and community members in active roles in the quality assurance and quality improvement systems.

State	Organization	FY2003 Award
California	State of California	$499,844
Colorado	Department of Human Services	$499,851
Connecticut	Department of Mental Retardation	$499,000
Delaware	Health and Social Services	$351,702
Georgia	Department of Human Resources	$475,000
Indiana	Family and Social Services Administration	$500,000
Maine	Department of Human Services	$500,000
Minnesota	Department of Human Services	$499,880
Missouri	Department of Health and Senior Services	$500,000
New York	New York State Department of Health	$495,811
North Carolina	Department of Health and Human Services	$475,100
Ohio	Department of Mental Retardation and Developmental Disabilities	$499,740
Oregon	Department of Human Services	$455,113
Pennsylvania	Department of Public Welfare	$498,650
South Carolina	Department of Disabilities and Special	$500,000
Tennessee	Department of Finance and Administration	$452,636
Texas	Department of Mental Health and Mental Retardation	$500,000
West Virginia	Department of Health and Human Resources	$499,995
Wisconsin	Department of Health and Family Services	$500,000
QAQI Total Awarded:		**$9,202,322**

[1]CMS awarded two types of technical assistance grants which are not included in the formative evaluation. Therefore, they will not be discussed in next year's annual report.

Exhibit C-2. Money Follows the Person Initiative

Purpose: Enable states to develop and implement strategies to reform the financing and service designs of state long-term support systems so that (1) a coherent package of State Plan and HCBS waiver services is available in a manner that permits funding to "follow the person" to the most appropriate and preferred setting, and (2) financing arrangements enable transition services for individuals who move between institution and community settings.

State	Organization	FY2003 Award
California	Department of Health Services	$750,000
Idaho	Division of Family and Community Services	$749,999
Maine	Department of Behavioral and Developmental Services	$750,000
Michigan	Department of Community Health	$746,650
Nevada	Department of Human Resources	$749,999
Pennsylvania	Department of Public Welfare	$698,211
Texas	Department of Human Services	$730,422
Washington	Department of Social and Health Services	$608,008
Wisconsin	Department of Health and Family Services	$743,813
MFP Total Awarded:		**$6,527,102**

Exhibit C-3. Independence Plus Initiative

Purpose: Assist states in meeting the Federal expectations established by the CMS for the approval of consumer-directed program waivers and demonstration projects within the *Independence Plus* framework. These expectations include person-centered planning, individual budgeting, self-directed supports (including financial management services and supports brokerage), and quality assurance and improvement systems (including the participant protections of emergency backup and viable incident management systems).

State	Organization	FY2003 Award
Colorado	Department of Health Care Policy and Financing	$391,137
Connecticut	Department of Mental Retardation	$175,000
Florida	Department of Children and Families	$501,801
Georgia	Department of Human Resources	$432,108
Idaho	Department of Health and Welfare	$499,643
Louisiana	Department of Health and Hospitals	$499,889
Maine	Department of Behavioral and Developmental Services	$500,000
Massachusetts	University of Massachusetts Medical School	$499,992
Michigan	Department of Community Health	$478,600
Missouri	Department of Mental Health	$427,461
Montana	Department of Public Health and Human Services	$499,963
Ohio	Department of Mental Retardation and Developmental Disabilities	$500,000
IP Total Awarded:		**$5,405,594**

Exhibit C-4. Community-Integrated Personal Assistance Services and Supports

Purpose: Improve personal assistance services that are consumer directed or offer maximum individual control. These C-PASS grants are not limited to supporting people transitioning from nursing facilities or to people who meet nursing facility level of care criteria.

State	Organization	FY2003 Award
Arizona	State of Arizona	$600,000
Connecticut	Department of Social Services	$595,349
Louisiana	Department of Health and Hospitals	$464,184
Massachusetts	Department of Mental Retardation	$579,178
Nebraska	Department of Health and Human Services	$600,000
Oregon	Oregon Health and Science University	$585,007
Texas	Department of Human Services	$599,763
Virginia	Virginia Commonwealth University	$513,557
CPASS Total Awarded:		**$4,537,038**

Exhibit C-5. Family-to-Family Health Care Information and Education Centers

Purpose: Increase access to and choice in HCBS for families who have children with special health care needs. The FTF grants will assist grantees in their efforts to (1) provide education and training opportunities for families of children with special health care needs, (2) develop and disseminate needed health care and HCBS information to families and providers, (3) collaborate with existing FTF centers to benefit children with special health care needs, and (4) promote a philosophy of individual and family-directed services.

State	Organization	FY2003 Award
Alaska	Stone Soup Group	$149,991
Colorado	Cerebral Palsy of Colorado	$150,000
Indiana	The Indiana Parent Information Network, Inc.	$150,000
Maryland	The Parents' Place of Maryland, Inc.	$150,000
Montana	Parents, Let's Unite for Kids	$150,000
Nevada	Family TIES of Nevada, Inc.	$150,000
New Jersey	Statewide Parent Advocacy Network of NJ, Inc.	$150,000
South Dakota	South Dakota Parent Connection	$150,000
Wisconsin	Family Voices of Wisconsin	$142,972
FTF Total Awarded:		**$1,342,963**

Exhibit C-6. Community-Based Treatment Alternatives for Children

Purpose: Assist states in their efforts to develop a comprehensive, community-based mental health service delivery system for children with serious emotional disturbance who would otherwise require care in a PRTF.

State	Organization	FY2003 Award
Illinois	Department of Human Service	$100,000
Maryland	Department of Health and Mental Hygiene	$100,000
Massachusetts	Commonwealth of Massachusetts	$100,000
Mississippi	Office of Governor	$99,000
Missouri	Department of Mental Health	$99,821
Texas	Health and Human Services Commission	$93,600
CTAC Total Awarded:		**$592,421**

Exhibit C-7. Respite for Children

Purpose: Enable states to conduct studies assessing the feasibility of developing respite projects for caregivers of children, through Medicaid or other funding streams, to help reduce the stresses families experience and to allow the family member to remain at home in the community and prevent or delay the use of more restrictive and expensive care.

State	Organization	FY2003 Award
Alabama	Department of Mental Health	$100,000
Arkansas	Department of Human Services	$75,000
Maryland	Department of Health and Mental Hygiene	$100,000
Michigan	Department of Community Health	$99,399
Oregon	Department of Human Services, Seniors and People with Disabilities	$99,274
Rhode Island	Department of Human Services	$100,000
RFC Total Awarded:		**$573,673**

Exhibit C-8. Respite for Adults

Purpose: Enable states to conduct studies assessing the feasibility of developing respite projects for caregivers of adults, through Medicaid or other funding streams, to help reduce the stresses families experience and to allow the family member to remain at home in the community and prevent or delay the use of more restrictive and expensive care.

State	Organization	FY2003 Award
California	Department of Mental Health	$100,000
New York	New York State Department of Health	$74,285
Rhode Island	Department of Human Services	$100,000
Ohio	Department of Aging	$73,854
RFA Total Awarded:		**$348,139**

Exhibit C-9. National State-to-State Technical Assistance Program for Community Living

Purpose: Assist Grantees and others to develop and implement effective programs for community living and to assure that resources and mechanisms are in place so that States, communities, providers, consumer groups, Grantees, and others can learn from each other, share effective practices, gain timely access to needed expertise, and disseminate the lessons learned so that all states and stakeholders may benefit.

State	Organization	FY2003 Award
New Jersey	Rutgers– the State University of New Jersey	$4,399,959

Exhibit C-10. Technical Assistance for Consumer Task Forces

Purpose: Provide technical assistance to the Consumer Task Forces Real Choice Systems Change grant projects. In partnership with the task forces, other consumers, states, CMS and others, the Grantee will work to significantly enhance the ability of task forces and other consumers to play a meaningful role in bringing about enduring improvements in long-term care services systems in their states.

State	Organization	FY2003 Award
Kansas	Topeka Independent Living Resource Center	$549,999